

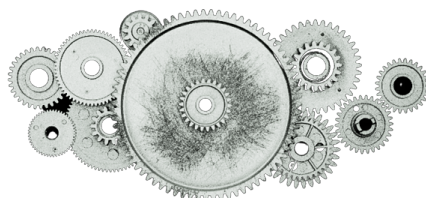


Leaders with Lived Experience Pilot Programme

Learning Partner Final report

July 2022

Introduction: purpose of report	3
Background	4
Who was funded?	6
Application process and working with TNCLF	8
Key themes	12
Defining LEx Leadership	12
Bringing people together	16
Methods of leadership development	18
Resilience and Flexibility	20
Successes	24
Number of beneficiaries	24
Skills and qualities	25
Sustainability and growth	27
Learning Opportunities	29
Limitations	29
Where do we go from here?	30
Appendix: Experiences from Wave 1 funding	32
Action on Postpartum Psychosis	32
Inclusion London	35
Inclusion North CIC	37
Inclusion Scotland	39
WITH	41
Migrant Centre NI	43



Introduction: Purpose of report

This report brings together learning gained over the two year period 2019-2021, relating to the pilot of The National Lottery Community Fund's (TNLCF) Lived Experience (LEx) Leadership fund.

EP: IC¹ was commissioned as TNLCF's 'learning partner' for the duration of the pilot, and this is the second report shared with TNLCF. The first was submitted in the summer of 2020 and fed back early learning about the grantees in real time while most of the grants were live.

This report is more reflective, looking back at the pilot and at what can be taken away as key learning about funding LEx.

This report starts with an outline of the grant, its history and its ambitions. It then explores recipients of the grant, looking at the types of organisations funded, alongside their focus, location and make up.

As TNLCF's learning partner, EP:IC was asked to contribute to their evolving knowledge about, and commitment to, LEx leadership by exploring a number of questions. Broadly speaking, there were two key areas of exploration and learning:

a. Gathering insights about the pilot programme itself (e.g. diving deeper into the motivations and aspirations of organisations for the pilot, and exploring their experiences of being a grantee, managed by TNLCF); and

b. Gaining a broader understanding of LEx Leadership which included questions such as:

What have the grants enabled for those with lived experience?

What have we learnt about the best methods by which to foster learning and development?

What impact is this work having on communities?

EP: IC explored these areas of learning through a number of means:

- reading or listening to grant applications to TNLCF and any subsequent information sent,
- holding one to one meetings with grantees,
- generating bespoke online surveys and polls,
- creating opportunities for network meetings for grantees,
- collecting information through blogs relating to their funding and project experience,
- collecting data through grantees' social media platforms and websites.

The programme duration meant that the pilot programme coincided with the onset of the COVID-19 pandemic and the first full year following the national lockdown. This significantly impacted upon the proposed projects, and on EP:IC's work as learning partners. Learning gained as a consequence of the pandemic is contained throughout this report.

[1] Empowering People: Inspiring Change (EP:IC) are an engagement and research organisation, working in the Lived Experience sector to promote positive change.

[2] Some organisations met with EP: IC multiple times, while others committed to only one meeting. One organisation did not meet with EP: IC at all.

Background

The LEx leadership pilot programme provided grants of between £20,000 and £50,000 to support LEx leadership within organisations. Eligibility criteria included any organisation that:

- was set up by a lived experience leader and/or
- was run by lived experience leaders and/or
- had a leadership reflecting those it sought to support.

The types of proposals invited were concerned with:

- leadership programmes or schemes related to developing leadership, such as mentoring, training or coaching
- methods by which to embed lived experience leadership within an organisation to enable the organisation to become more sustainable (e.g. improving governance/decision-making structures, succession planning and support packages for wellbeing)
- challenging and championing meaningful ways in which to embed lived experience leadership in service design and delivery
- projects bringing lived experience expertise to a theme, location, service or sector in which it is under-represented.

The fund was inspired in part by the published work of Baljeet Sandhu,³ entitled *The Benefits of Lived Experience*. In her research, Sandhu connected with over 80 social sector leaders and 12 senior leaders in funding and philanthropy in both the UK and USA, exploring how the social sector cultivates and develops social impact work with experts by experience.

Her work revealed a number of challenges in the involvement of experts by experience in change-making roles, including tokenism (and shoe-horning service user feedback into pre-planned policy change), a preference to look backwards through storytelling rather than looking forward to social change, and a stagnancy and invisibility of discussions concerning power, systems and intersectionality in society. All these can act to block and hinder true social change.

Sandhu's report also delineates how LEx leaders in social change are often overlooked in decision-making circles, set apart from meaningful collaboration through "othering" and unhelpful stereotyping. She concluded that the value of LEx leadership within the social sector was neither universally recognised nor sufficiently elevated.

Dawn Austwick, former Chief Executive of TNLCF, set⁴ out a commitment to LEx leadership and "people in the lead" in a 2018 blog, speaking about a precursor project, in which LEx leaders were on the steering committee, acting as facilitators as well as programme grantees. Austwick said:

[3] www.thelivedexperience.org

[4] Blog posts | The National Lottery Community Fund (tnlcommunityfund.org.uk)

“People with first-hand experience of living with an issue are best placed to identify and shape potential solutions, and this scheme is about unlocking their potential. Drawing on the wide pool of life experience and hands-on expertise currently going untapped in the UK, UnLtd and TSIP are taking an important step towards capturing this knowledge to ensure people’s deep understanding of the challenges they face is at the heart of making change happen.”

TNLCF's commitment to putting “people in the lead” extended to the development of this project which utilised an innovative participatory programme design approach. LEx leaders from the social justice sector themselves played a significant role in the design and approach of the fund. Leaders were brought together through a series of large-scale convening events across the UK. From our interviews with the programme team, we heard how this co-production approach to the fund design impacted on shifts in thinking and culture internally.

“I guess at that point, in 2017, it wasn’t something that was spoken about too much, more in a sense of supporting projects run by communities or communities in the lead. We spoke about lived experience in terms of representation... kind of story telling probably from professional led organisations, and then suddenly we were just thrown into a totally different kind of way of working, and we were thinking about power and where that’s held and how that needed to be challenged.”

3

The impact of this approach on the community perception of TNCLF and its proximity to community issues was also keenly felt; a lived experience leader who attended one of the convenings (subsequently funded in the pilot programme) stated:

“Very interesting indeed to be invited to a 2 day residential to discuss with numerous other LEx Leaders the scope and design of a brand new fund. Most of us had always felt that funds such as TNCLF were distant from us; It felt very different for the Lottery staff to be there just listening to us, not informing us of the plans, but genuinely listening and taking on board what we were saying. For many of us it was a new experience and one that filled us with hope that our expertise was moving from the shadows to the forefront of design and delivery. It felt significant and they felt more approachable and relevant.”

As a result, the language used in the funding call, the easy to access application process and the tone of the approach chimed with LEx leaders in a manner which was unprecedented. Cash-strapped, delivery orientated community organisations rarely enjoy sufficient core costs allocation to enable time and resources to be made available for specific leadership development activity, but this was recognised thanks to the co-design process. The potential and far ranging impact of the fund investment was made clear through the convenings and, in part, this impact was about how LEx was evolving within the sector.

“We hope we can support people locally or working in funding to support those just with basics about what is lived experience leadership? How is this different to service user involvement, what is the kind of language we should be interrogating from funding applications, what does a governance structure look like; why is that important? And to

start moving the thinking on internally about how people are thinking and conceptualising lived experience and hopefully moving it on a bit; and developing metrics that go beyond how many people with lived experience are there in your organisation?"

LEx leaders also formed an integral part of the decision-making and award process, sitting with diverse Lottery programme team staff on funding decision-making panels.

In total, 20 grants were awarded in April/May 2019 spanning a broad spectrum of social needs and interests, lasting up to two years.

"It is now pretty unthinkable (and most definitely frowned upon) if any significant activity does not include the voice of Lived Experience. While there is still work to do to ensure true co-production takes place – rather than more token involvement – there has definitely been a cultural shift."

Who was funded?

The cohort was comprised of 20 organisations, with national, regional, multi-site and local briefs, based in all four countries of the UK, as outlined in the chart below.

UK wide organisations

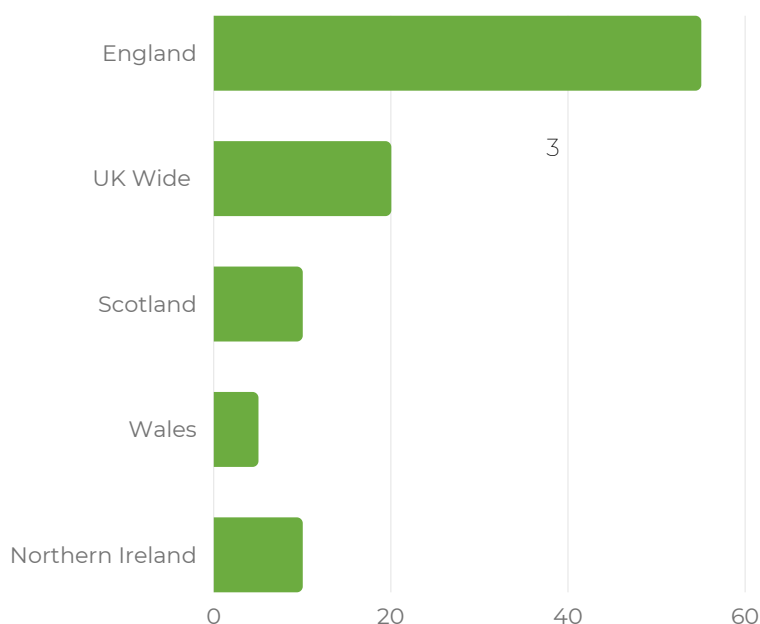
- Action on Postpartum Psychosis
- The Care Leaders
- Kinfolk
- User Voice

England

- 4 Front Project
- Sour Lemons
- Alliance for Inclusive Education
- Muslim Women's Council
- Inclusion North CIC
- Emerging Futures
- Girl Dreamer
- Comics Youth
- Inclusion London
- Community Led Initiatives
- BAC-IN

Northern Ireland

- Migrant Centre NI



Scotland

- Scottish Recovery Consortium
- Scotland Inclusion

Wales

- Welsh Institute of Therapeutic Horsemanship

The stated focus of each of the grantees is listed in the table, although a key learning point of the programme has been that LEX leaders and lived experience-led organisations rarely fit into neat sector-specific silos and intuitively and organisationally understand and work with intersectionality.

LEX leaders from the social justice sectors live in, and have experience of, a deep personal and professional understanding of intersectionality. They understand that there are more often than not, a presenting problem is not the full story and as such, solutions must be diverse and multifaceted. Therefore, these organisations have multiple work streams and organisational knowledge that cut across many sector silos.

The work of CLI and User Voice, for instance, might primarily be seen as being concerned with criminal justice, but in practice spans those experiencing homelessness, mental ill health, social isolation, education, physical wellbeing and financial disadvantage.

“Well we say to funders we work with people in the criminal justice system, but essentially that means knowing about homelessness, substance misuse, trauma, mental health, physical health, brain injury, dyslexia, the lot!”

Therefore, despite there being key sectors associated with each organisation, in actual delivery and lived experience practice expertise, significant crossovers and understandings are evident.

For example, BAC-IN, Migrant Centre NI and the Muslim Women’s Council have reported that, despite not being the primary focus, mental wellbeing and physical health feature within their work plans. Further, this has increasingly been

Organisation	Sector
User Voice	Criminal Justice System (CJS)
Community Led Initiatives. (CLI)	CJS, multiple complex needs
4 Front project	CJS, race and social inequality
Welsh Institute of Therapeutic Horsemanship (WITH)	Multiple and complex needs
Bac-In	Multiple and complex needs
Scottish Recovery Consortium	Substance misuse
Emerging Futures	Substance misuse
Sour Lemons	Marginalised youths and Arts
Comics Youth	Marginalised youths and Arts
Sub-Sahara Advisory Panel	Race/BAME Leadership
Girl Dreamer	Race/BAME Leadership
Muslim Women's Council	Race/BAME Leadership
Kinfolk	Race/BAME Leadership and community organising
Inclusion London	Disability
Inclusion North	Disability
Alliance for Inclusive Education (ALLFIE)	Disability
Inclusion Scotland	Disability
Action on Postpartum	Mental health
Migrant Centre NI	Refugee and migrant rights
The Care Leaders	Care leavers

the case during the pandemic, when mental health has become a more pressing focus for many of the organisations funded by this programme.

“Our cohort of LAVA Leaders have expressed that they are particularly interested in addressing issues of mental health in migrant and BME communities and are keen to develop a final project which addresses this issue through health and wellness programming - we are excited to see what form this takes.”

Additionally, the work of ALLFIE – prominent in the disability sector – also evidences sophisticated lived, learnt and practice experience in racial justice and equity work.

Of the 20 funded organisations, an overwhelming majority identified as working with people facing multiple challenges and this intersectionality is an essential understanding that is critical to their work but often overlooked by funders. It may explain how lived experience-led organisations can fail to fit into neat thematic funding streams.

We recognise that seven of the 20 (35%) organisations are led by Black and minority ethnic leaders. When COVID-19 and the Black Lives Matter movement protests throughout 2020 spotlighted the funding community to look at their track record in funding awards directed at communities of colour, the pilot LEx Leaders fund emerged as having successfully navigated the challenges that faced other funders in terms of the inequitable distribution of funds to such communities.

The cohort also supported both adults and young people; with seven of the 20 organisations specifically focusing on building LEx leadership and representation in the youth sector. Despite our separation in the table above of project descriptors by age profile, we observed that an intergenerational learning and support focus was a factor in some projects. Some projects expressed a clear intention to ensure cross pollination and knowledge exchange between age groups, speaking of the necessity to encourage youth capacity to “carry the baton” forward and transfer knowledge to young people relating to the story that has gone before them, of the challenges faced and successes achieved. Girl Dreamer, Allfie and Comics Youth all recognised how working with young people with lived experience becomes a mutual learning opportunity for those in different age groups, whilst CLI observed the impact of the CEO and an emerging leader within the organisation meeting up for knowledge exchange.

Only three organisations were focused on developing senior leadership and it was these three organisations that identified how their work was able to evidence a significant and definable systems change impact.

Application process and working with TNLCF

All the organisations we engaged with (19 out of the 20) described the pilot programme as being easy to apply to. Through an online survey later in the programme, we explored the application and grant management process further. All stated that the TNLCF application

was clearly worded and they understood what was required. Most agreed that the tone and simplicity of the form conveyed the intention of reducing time-consuming and complicated applications, and that the funder had thought primarily of applicants, enabling less experienced and smaller organisations to participate. This created an immediate and intuitive sense of connection between the TNCLF's ambition, insight and understanding, and the potential grantee.

"The application is short, clear and concise. I think it is very reflective of what the grant is about simply because if you ask more information e.g. log frames, inputs, outputs etc then there you are, just another funder looking at figures and numbers rather than putting people and people's needs in the lead."

"I think the wording is fine as it is, it says what is in the tin and that lived experiences are central to not just the individuals benefiting from it but also the organisation themselves."

Some grantees welcomed the online application process and the ability to submit applications in different forms such as a video. However, two respondents raised a query as to whether the brevity of the form enabled organisations to fully outline their values and plans.

"[My] only reflection would be that I think a lot of lived experience work is about modelling different mechanisms of engagement as well as centring grassroots solutions. I don't necessarily know that the form lends itself to speaking about how your work looks and feels different in the relationships with the individuals and communities you're working with – i.e. how is the power dynamic of service provider/service user different from in a more traditional service provision model."

The EP: IC team considered if this comment might speak to tensions inherent in understanding the definition of a lived experience-led organisation and a lived experience-led project, a point which is picked up in a later section of this report.

Other responses to the form are as follows:

"The application form was very simple, this is great for ease of applying. I wouldn't say you should or shouldn't change anything. For me simple application forms are a double edge sword; you make them too easy then anyone can apply, and this could reduce the standard of applications and overwhelm the short-listing process. But if it's too complicated to apply you will marginalise people with lived experience from applying."

"I would have liked to have had more space to explain the details of the project as I felt that I wanted to say more, however this is more a preference of mine and not a recommendation."

Respondents identified that positive and enabling relationships were developed with the TNCLF grant manager and team, appreciating the accessibility of the grant manager, who was available by phone and email very easily. They further appreciated the individualised support they experienced and responsiveness to queries. For some, this was their first receipt of major funding, and they expressed gratitude and assistance for support received

in the early days with issues relating to bank accounts and project plans. They described communication between themselves and TNLCF as open and beneficial, and felt comfortable to approach when needed.

“Good open communication with the Lottery Manager as and when we needed it both by phone and by email.”

“The support from the grant manager has been very useful.”

“In all honesty we can say that everything has worked well. We have found the whole process straightforward and easy to understand and negotiate and would have felt able to ask for support at any stage had that not been the case.”

Trust emerged as a common theme when reflecting on the relationship between TNLCF and grantees. One respondent replied:

“We appreciate the amount of trust put in us as an organisation to carry out the project. This means that we can actually focus on the work as opposed to monitoring paperwork, something that takes up a lot of time on other projects from different funders.”

Grantee partners were also asked how they felt about the entire grant process. Some respondents reported it took too long between application submission to award; and then from award to commencement of their project. These grant holders suggested expectations could be better managed in more explicit time frame guidance going forward, especially for those organisations new to TNLCF funding. They believed improved understanding of this would enable them to forward plan more effectively.

Three projects suggested, as a learning point, a more hands-on approach to grant management for those unused to working with a funder, especially within the context of the trusting relationship the TNLCF team had built with programme grantees. They felt that some LEx projects may have experienced anxiety in raising any barriers or challenges; and newer grant holders might benefit from guidance about how to collect and report on outcomes, as well as about the process of reporting changes to the project plan.

“The reporting back to National Lottery could be improved. We are aware that as this is a pilot programme the reporting has been left to projects to decide how to do this, but this may exclude people who are not familiar with reporting back to grant givers. Although TNL are relaxed about this, some leaders with lived experience may become anxious with little guidance.”

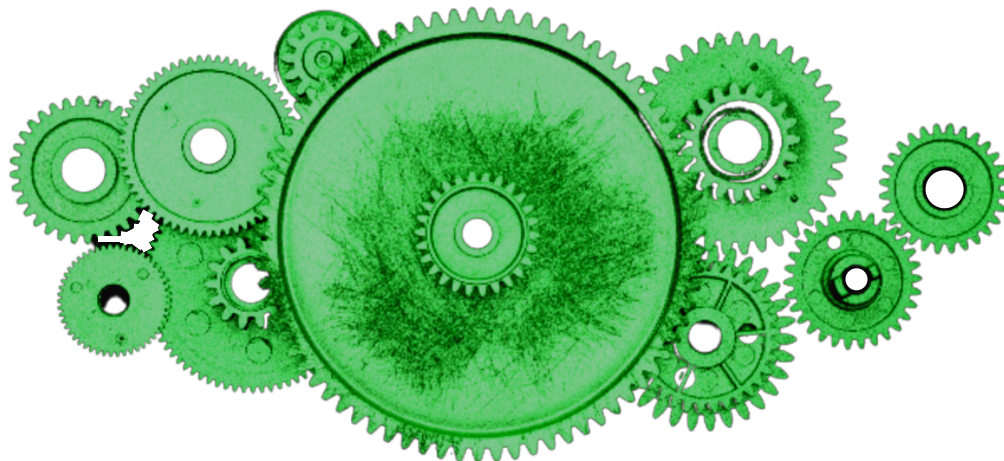
“Although being very straight forward, I think that we could have been pressed for a little more detail in our project plan. Along with this some guidance on the tolerance allowed for changing the plan.”

“More coaching. We have not accessed any coaching as we are capable and experienced in project management – however less experienced leaders will benefit from a clear coaching offer with clear terms of reference.”

Some suggestions were made that the pilot programme should become a mainstream programme, should extend the number of grant awards, encourage partnerships to develop and increase the duration of the grants to embed learning. It was suggested that TNLCF could focus on building partnerships, encouraging collaborations, archiving and promoting project outcomes as well as investing in the infrastructure of the broader LEx movement. However, some anxiety arose around the conclusion of the project, whereby new learning had emerged for organisations and LEx leaders were developing, but there was no continuation funding available.

Importantly to grantees, many found the pilot programme to be validation by a major funder of the power of LEx leadership and this was overwhelmingly welcomed.

“This is a wonderful programme and I think there is little to change in relation to the purpose, criteria and wording of the programme but I believe TNLCF can be ambitious and bold about the programme and expand its work.”



Key themes

Throughout the next section, we focus on some of the emerging themes from the pilot phase:

- Defining LEx leadership
- Bringing people together
- Methods of leadership development
- Resilience and flexibility

1

Defining LEx leadership

The funding call specifically defined the meaning of lived experience for the purpose of the fund and a LEx leader was defined by TNCLF within the funding criteria as someone who “uses their first-hand experience of a social issue to create positive change for, and with, communities and people they share those experiences with.”

Our interviews with key members of the TNCLF programme team highlighted initial disparities in how some potential applicants understood the term 'lived experience', particularly in relation to leadership.

Indeed, the TNCLF project team explained one of the primary requests from potential applicants related to understanding the definition further prior to submission of an application. For some organisations, understanding and connecting with the terminology had led to them self-defining differently, which had been positive for many and had also opened up opportunities.

“Since our inception 10 years ago we have pretty much been a lived experience organisation although it is only lately that we have used that terminology. Prior to 2018 we would probably have talked more in terms of being a recovery-focused organisation with the majority of our team being in addiction recovery. The shift in terminology has been helpful because, although addiction recovery is still central to what we do, we are now making common cause with other lived experience organisations.”

Further, this definition of a LEx leader did not fully align to organisations which were partially LEx-led, although they remained eligible for funding within the fund parameters.

Looking at the pilot cohort, there were variations in the extent to which they were LEx-led, from board level to senior management and throughout the management structure.

Of the 20 grant holding organisations, 13 identified as fully run and delivered by people with lived experience. The following table outlines how lived experience is utilised and enabled in each grantee.

Organisation	Perceptions of leadership	EP: IC reflections
Migrant Centre NI	LEx-led	Founded by a LEx leader and labour rights leader. The SMT and board are no longer LEx. However, some frontline staff are and they wish to develop LEx leaders from within the communities they serve.
WITH	LEx-led	LEx-led
Sub-Sahara Advisory Panel	LEx-led	LEx-led
Scottish Recovery Consortium	LEx-led	Definition of lived experience broadened to include the new term “recoverist” to facilitate involvement of those with familial experience.
Inclusion Scotland	LEx-led	50% of board has a disability, but it was unclear whether the project lead has LEx, which has led to some challenges within the project.
Action on Postpartum Psychosis	LEx-led	Mixed
Care Leaders	LEx-led	LEx-led
Kinfolk	LEx-led	LEx-led
User Voice	LEx-led	LEx-led
4 Front Project	LEx-led	LEx-led
Sour Lemons	LEx-led	LEx-led
ALLFIE	LEx-led	LEx-led
Muslim Women's Council	LEx-led	LEx-led
Inclusion North CIC	LEx-led and learned experience integrated	51% of the board are LEx, as are most of the staff and management team.
Girl Dreamer	LEx-led and learned experience integrated	Two thirds of team are LEx
Emerging Futures	LEx-led	LEx-led
Comics Youth	LEx-led	LEx-led
Inclusion London	LEx-led	LEx-led
CLI	LEx-led and learned experience integrated	LEx-led
BAC-IN	LEx-led after a period of mixed team	LEx-led

A degree of confusion became evident across the cohort as to the definition of a lived experience-led organisation, and how this can be decided upon.

We noted how some organisations are founded by a person with lived experience of the social issue in focus and are fully staffed by LEx leaders. However, other organisations, although founded and/or led by LEx leaders, are simultaneously populated and staffed by individuals without the same lived experiences.

LEx leadership through the founder may not be reflected in the board and governance of the organisation and it may be that, even when led by a LEx leader, the day to day delivery and direction of the organisation is not always wholly LEx-led.

Some organisations in the disability field stated that, since their board was either 51% or 50% comprised of people with a disability, this enabled the organisation to be described as “lived experience-led”.

“We have a Board of Directors and an Advisory Council. 50% of the places on each of these governing bodies has to be taken by a person with lived experience of a learning disability or autism. The Board of Directors is led by two Co Chairs. One of the Co Chairs must have lived experience of a learning disability or autism.”

One organisation, Inclusion North, did not start the project fully LEx-led, but used the award to build LEx leadership within their own team and beyond, integrating individuals with lived experience of a learning disability or autism within their staff team as a result of the project. This was seen positively.

There were concerns over how organisations presented. Some organisations suggested that certain larger organisations in the sector were positioning themselves as LEx-led when this was not the case. This was a source of frustration and was highlighted as something for TNLCF to be mindful of in the future.

“The sector is gate kept by large orgs that pretend to be LEx led but aren’t.”

Understanding the subtext behind such comments, and whether this refers to how LEx-led organisations at scale may risk distancing themselves from the values inherent in smaller community organisations, merits further investigation. Similarly, some leaders felt that it was becoming commonplace to witness the misappropriation of the LEx label for personal and organisational gain, warning against professionals who have worked in a social justice field claiming lived experience of the issue by virtue of proximity.

“LEx does become fashionable and it creates divides. As soon as you label something this is often a result.”

Alongside this, we observed concerns raised by some partners surrounding “political correctness” and purity of definition, which were experienced as somewhat authoritarian and divisive. Some grantees felt that it was unhelpful to attempt to “police” definitions and were keen instead for those in the sector to concentrate on the work being done.

“People policing what lived experience means is an absolute problem, you can’t police that. I am aware of that in the sector, I have been communicated to about this and have met it with a bit of fury.”

The 4 Front Project reported they had spent time and energy furthering their own understanding of the definition and experience of an organisation that defines itself as LEx-led. The 4 Front Project considered how the division between non LEx staff and service-users may create an unnecessary barrier, impeding the energy and fluidity of a LEx-led organisation. They spent grant monies buying in training from an external organisation (The Science of Violence), to deepen their understanding of systemic oppression and to consider how the structure of an organisation (including their own LEx organisation) may simulate existing hierarchical and oppressive power structures, and thus limit its impact on both individuals and systems.

The 4 Front Project is now considering how it understands itself internally as a “membership organisation”, blurring the distinctions between service provider and service user, and recognises that its positionality within the sector may change as a consequence.

There remains work to do on understanding definitions more fully. However, for the majority, the definition of LEx leadership (as defined in the pilot programme) was a useful basis on which to centre the authentic and powerful role of LEx leadership. This is an emerging sector evolving in a non-linear way, and we must continue to listen and observe as the pace of development and innovation continues.

One such development is the question of how current ‘living experiences’ differs from experiences that have passed, within the definition of LEx leadership and LEx-led organisations. For example, Comics Youth reflected whether as a youth focused organisation initially founded by young LEx leaders, they now have outdated lived experience. However, passed experiences remained relevant and important to enabling young people to develop as leaders. Such reflections and willingness to consider options demonstrate a clear will for the organisation to develop, rather than a will to blindly hold on to its leadership. Similarly, Sour Lemons reflected on the relative youth of the ‘Elders’ within the organisation. In so doing, both organisations recognised how young people had transitioned from service recipients to leading cultural change within each organisation. Comics Youth told us:

“One of the biggest learning points for us was to be aware that although the lived experiences that led to the formation of the organisation is similar to that of the YP we support, it was important to remember that YP’s experiences are however culturally different due to the systems and structures which underpin their ‘generation’. We needed to remember that there is a marked difference in the lived experiences of millennials and generation z! It was fascinating for us to explore the reclamation of language in the way we approached not only communication within the project itself, but as a wider grounding for the organisation as a whole.”

Some grantees commented on how more established LEx-led organisations had become so enmeshed in the mainstream system that their lived experience roots and history may have become diluted, thereby inhibiting the radical and changemaker edge of their LEx leaders.

“A lot of LEX orgs are ticking boxes, antiquated. Rigid. LEX orgs need to be progressive, keep up with the changes, truly listen and respond to be progressive.”

“Do they need all the staffing they have currently if they want to be properly young people led? They should consider changing the model so young people fall into the adult paid roles to stay true to being young people led.”

Grantee partners shared various observations surrounding the difference (or not) between a leader with passed lived experience and a leader currently immersed in the experience. Many senior leaders described the lived experience (once reflected upon) as a tool which they utilise constantly in their leadership and therefore it is always relevant. Others, such as those in the racial justice space or disability sector, will always be “living” their experience.

Discussions focused on whether the distinction matters or whether both experiences apply simultaneously, as well as whether such a distinction could affect leadership qualities, style, vibrancy, political orientation and vitality of an organisation.

Bringing people together

In seven organisations, there was evidence of “blended” teams, mixing LEX with non-LEX. These teams were spoken of with high regard, in terms of providing the necessary mix of skills and experience to achieve their mission. For example, in APP, alongside women who have themselves been through postpartum psychosis, there are also academics who can medically advise on the condition. They told us:

“We feel our model of combining lived experience expertise with academic rigour, clinical and management experience and expertise is the gold standard for organisations.”

Community Led Initiative (CLI) also reported enthusiastically about the lived and learned (non-lived) experience within their team and its impact.

“We have people in our team who have spent most of their lives taking risks, which proves very beneficial when trying out something new that others may be unsure of due to the unknown outcomes. When you add this with those who have led more of a risk averse life, taking more care and following rules and procedures, this brings the structure and careful planning to ensure an all-around team effort that everybody gets satisfaction and security from.”

It was unclear whether LEX leadership thrived more effectively within an exclusively lived experience environment or within “blended” teams, where non-lived experience professionals worked alongside lived experience leaders.

Successful “blended” approaches were observed, characterised by a cross-pollination of learning and continuous knowledge exchange, bringing about a culture of optimism and respect. This was clearly evident in the work of the Scottish Recovery Consortium, where new language emerged, including the term “recoverist” to describe a person without lived experience but active within the organisation.

While we currently have staff with direct lived experience in our key roles we have always recognised the value of indirect experience i.e. addiction does not only affect the individual but has an impact on those close to them and those who work in the field. While we place a high value on people in recovery and their lived experience we have also developed the term recoverist (recovery activist) as an inclusive term that covers everyone who is actively engaged in recovery related activity and shares our organisational values and mission. Therefore, people who do not have lived experience (or do not want to disclose it) are also a valued part of the work we do. So, for example, our Board has a mixture of people with direct and indirect lived experience and people who would identify as 'recoverists' – this ensures we have balance at strategic level in terms of different perspectives while remaining true to our values as a lived experience organisation."

However, this approach did not work for all. BAC-IN described how they experimented with expanding their team to include those without lived experience but returned to recruiting only those with lived experience of addiction. They had found attempting to blend lived experience with a learned expertise challenging, and that it created tensions and difficulties.

"This dynamic proved to be very challenging for us, and something we ultimately regretted doing. There were communication issues, staff without lived experience were unable to engage effectively with our service users and our peer led team, we were worlds apart in terms of empathy, psychological relatedness and interpersonal connection which is key in supporting and transforming the lives of people with lived experience."

Irrespective of the make of of the team in relation to lived experience, the concept of bringing people together was central to the projects being undertaken; LEx leaders coming together to undertake leadership programmes, to receive mentoring from other LEx leaders (both internal and external to the organisation) and to learn from others (whether LEx or not).

There was clear value in building networks of LEx leaders. Speaking to beneficiaries highlighted the value of leadership programmes designed specifically by LEx leaders for LEx leaders. We learnt how systemic barriers across the social sector have positioned many LEx leaders as a vulnerable or challenging group and how this creates hesitation in joining sector conversations. When lived experience leaders met each other, they shared experiences which created a sense of trust and connection rather than of competition.

The Scottish Recovery Consortium launched a sophisticated LERN Network to engage with over 80 dispersed local and regional leaders in the substance misuse field, and through this have achieved significant strategic impact since the LERN Network launch in July 2019.

Kinfolk also reported how networks were the lynchpin of effective community organising and leadership for change. Participants and organisations have acknowledged the benefits of social interaction, witnessing commonalities across diverse and differing life experiences. The importance of network building, at personal, organisational and national levels, has been a visible commonality across organisations we have connected with on the learning journey.

Methods of leadership development

Pilot partners delivered leadership capacity building and training in different ways, reflecting the diversity of leaders benefiting from the funding. Some examples included;

- formal training programmes from external partners
- hosting or attending a conference.
- collective leadership development and capacity building
- inter-generational knowledge exchange.
- building LEx representation in governance models
- building middle management and frontline capacity
- coaching
- experiential learning as a vehicle for development
- creating a leadership programme for project beneficiaries/service users.

One organisation, APP, used some of the fund to access individual support externally, which was shown to have a substantial and positive impact on their ability to teamwork.

“I’ve found the counselling I accessed really helpful. I have found it so helpful to have a place completely for me, a space to think more deeply about everything in my life and it has definitely had a massive positive impact on my own mental health and emotional wellbeing. It is something I wouldn’t have been able to afford myself, without the grant.”

The pilot demonstrated that LEx leaders often developed bespoke training, adapted to their context, needs and organisational ambitions. These grantees used the fund to design their own specific training models or to adapt those already in existence. Some of the projects developed toolkits to future proof LEx leadership within their respective organisations.

We observed that network approaches specifically supported senior leaders to make policy impact at a strategic level and that LEx leaders readily and easily gravitate towards, and flourish within, collectives and peer-led groups.

The involvement of peers and the availability of experienced LEx leaders as educators was found to be extremely powerful for several reasons, one of which was mentioned in the previous section in relation to individuals feeling safer and more free to express themselves.

“The most important success was creating safe and brave spaces to explore the really hard stuff... people on the programme were able to dive down deep into the damage years of discrimination has done to them and gradually work out what they had control over and

what they can challenge. It was humbling, particularly in facilitated peer support meetings, to see people prepared to open up and take risks to explore really very painful experiences and barriers they face so that they could find new solutions together. It was clear that for some of the participants, being given support to take power and control was a transformative experience.”

“I could ask things I had always wanted to ask, but never felt I should do. Questions about whether something was normal or a consequence of prejudice. I could check that. I felt comfortable to dig a bit deeper and explore my own journey in a safe space, something I would never get on a traditional leadership programme.”

This mutual trust and intrinsic respect of people and their journeys allowed individuals to challenge certain assumptions they held, and test out options, without fear of being judged or “seen the wrong way”. Participants on one programme reported that the involvement of lived experience tutors was very inspiring, removing any doubts about whether they could complete the programme.

“... the life experience of the individual is a massive benefit to organisations as it brings a more diverse viewpoint and approach to ways of working that may not be there if the leadership team is quite similar in background and experience. There is a higher degree of credibility when trying to influence change on a broader scale if the person themselves has the personal experience to evidence change.”

“It did much more for me than allowing me to be successful in a change plan. It allowed me to be supported and guided by professionals who actually understood how to develop someone like me which feels like a unique opportunity and hope others who are in a similar situation can experience... I now know I have the skills and ability but knew something was stopping me fulfilling my best but I just couldn’t quite figure out what.”

Allfie designed an intergenerational learning programme for young leaders living with a disability, bringing them together with elders so that both sides were able to grow and learn from the experience of others.

“Through the National Lottery Funding we were able to create an opportunity for ALLFIE to work with the RIPStars group of young Disabled people to share experiences, stories and intergenerational learning with Disabled leaders from across England. We created space to understand the important role Disabled people have played in creating our own history of change, through activism and helping to change the narrative about our experiences and contributions to society. We observed that the grant created space for organisations to not only build leadership capacity but also created space for some organisations to think about long term organisational direction and shape, pushing boundaries and extending thought leadership.”

Clearly, beneficiaries value development opportunities where the experiences of adversity are re-framed as positive attributes and ‘unteachable skills. This re-framing of experiences enabled increased feelings of self-worth and self-resolve; affirming visions of hopeful optimism for the future. This motivated them to consider launching new businesses, engage in work or volunteering (sometimes for the first time) or stretch to new heights of influence and innovation in their personal life and wider communities.

Throughout the pilot we recognised how senior leaders increased in both confidence and curiosity to engage in training within and outside of the LEx sector. They reflected how they were more open to different perspectives, and integrating them with confidence into their organisational approaches and delivery.

Our observation on the assessment and comparison of the models of leadership development activity is that this area requires further exploration and we hope to report on this in the next phase of the fund.

Resilience and flexibility

Many of the communities in which pilot partners were living and working were disproportionately affected by COVID-19. On a personal level, some grantees suffered bereavements directly as a result of COVID-19, and for understandable reasons this impacted on the delivery of projects.

Others were advised to shield and subsequently saw no friends, colleagues or loved ones for several months. Those with physical or mental health needs were also acutely affected which again directly impacted on the pace and shape of how projects developed.

“Whilst the past year has been a difficult time for everyone, the worries and anxieties arising from the pandemic are even more acute for those managing ongoing mental health diagnoses.”

Yet, in contrast to the suspension of many services and changeable regional and national lockdowns across the country in Spring 2020, we witnessed tremendous mobility and resilience within our LEx leader cohort. They recognised that the

need in their communities would not disappear in the wake of a pandemic; in fact, quite the opposite. More than ever, LEx leaders attempted to build community cohesion and connection; against a tide of social and professional isolation. One organisation told us:

“Having this programme around whilst experiencing lockdown happened to be even more important and useful for the young women as they had a community, a safe space and some remnant of normality, as when they were undertaking the programme before COVID-19 hit.”

Professionally, many grantees were working in disadvantaged communities, which bore the brunt of the pandemic in terms of reduced hours / unemployment, displaced or suspended services and clear health inequalities. We were told by one partner:

“I’ve never seen anything like it. It’s harrowing. But I suppose at least that shows we are reaching the right people at the right time.”

As such, workloads for most partners increased rather than decreased, as work was put into supporting those in their communities. Most projects were able to continue. Only a few partners were not able to pivot their project plans because they required access to external leadership training which was cancelled due to the pandemic, a situation entirely out of their control.

Our learning observations and analysis lead us to report that these organisations are full of people who rise to adversity with resilience, patience, passion and purpose. No organisation reported a failure to resolve any challenge faced during the delivery of their programme; even if the solution was to pause their projects. When

staff became ill, they reframed the delivery to accommodate; when participants were struggling with agreed timings and pace or childcare commitments, they adapted to meet need, in some instances adding additional costs to delivery. During COVID-19, these organisations adjusted and persevered.

LEx leaders have demonstrated a deep-rooted commitment to their communities, borne not only from their own experiences but out of the hope that they can enable others to follow a less resistant path. We were not surprised by this, but COVID-19 and the resultant social disruption presented us with a unique opportunity to see this commitment in action.

“It hasn’t been easy, it has been a struggle but I think as people from grass roots we’ve always had to learn and adapt cos we have had to fight for our voices to be heard.”

The sense of determination was palpable and, despite the challenges facing grantees, they were not daunted by the experience of the pandemic once they had understood the limitations in which they were required to work. This attitude represents a fundamental quality of LEx teams, as described by two of the grantees below.

“We’ve been through worse, whatever the challenge, we know we can get through it as we have done it before, we will do it again.”

“The journey for us so far has not been smooth sailing. However, that is what makes this project even more exciting. As an organisation, we pride ourselves on taking on challenges that others may find daunting. We are also not fearful of when things don’t go to plan. When this happens, we come together as a team, reflect and learn from every challenge we face and then share this learning with others outside our organisation.”

We observed these organisations are not overly rooted in bureaucratic process. Rather, they are adaptable, flexible organisations that serve their specific communities and wish to drive social change to improve the lives of those they represent and serve. We saw LEx-led organisations act responsively and quickly through the rapid re-organisation of their work and teams. They pivoted their work plans, sometimes substantially, in order to navigate through the pandemic, commit to the programme and continue with their projects. Two partners summed up why this approach was needed:

“If we don’t change, the other alternative is the money could be wasted.”

“There wasn’t an option to stop. The women would do anything to see it happen.”

Creativity and innovation were key. The speed at which the pilot partners adapted plans was impressive and stood in contrast to many other non-LEx-led organisations who closed their doors or initiated skeleton services for many months.

For most organisations, adaptations strengthened internal working methods and offered much needed flexible participation from their communities. Instances include those who

found it difficult to travel and those who were stretched over large geographical areas and who were therefore able to come together like never before, furthering their reach.

“What we found was that the statutory and quite a lot of the third sectors were very slow, they just shut down. But what happened in our community is that all of us went online like that (clicks fingers). It was zoom meetings, it was making zoom pizzas and support groups online so actually it has really raised our profile... Communities act much quicker and they are much more innovative and they are much more nimble so we can go from a face to face group to an online group like that (clicks fingers).”

An example was how Care Leaders developed a newsletter to be sent to children with small gifts, in appreciation of how these children were likely to be struggling during the pandemic. They also secured funding from the Virtual School within Oxfordshire County Council to commission five artists to develop a “challenge” that young people could complete at home.

Sour Lemons provided insight into how their projects had changed as a result of the pandemic – for instance, a pre-planned “supper club” with a pro-bono external speaker became a paid inspirational speaker session over a virtual platform with a meal delivered to all attendees at home.

We saw organisations develop their involvement and engagement methods, including a range of media and hybrid remote and face to face meetings (when regional restrictions allowed) which often expanded on the original offer to those being served.

Budgets were scrutinised and repurposed accordingly, with support from TNLCF. This support and flexibility was always welcomed by pilot partners, which could have meant the difference between success or failure for some projects.

It was not only the project leads who shifted their approach. Some beneficiaries were placed outside of their comfort zone, needing for the first time to access online platforms in order to continue with the programme. This required some of the cohort to address the issue of digital exclusion, relating to both financial disadvantage and accessibility. One beneficiary told us:

“Looking back I never thought I would be able to even get onto the zoom, let alone talk on one.”

Digital exclusion was confronted head on and programmes adapted. Programme leaders worked with their cohorts to identify what was needed in order to make the programme work. Two disability sector organisations funded a digital notetaker so as to provide as much assistance as possible to their young leaders with access requirements.

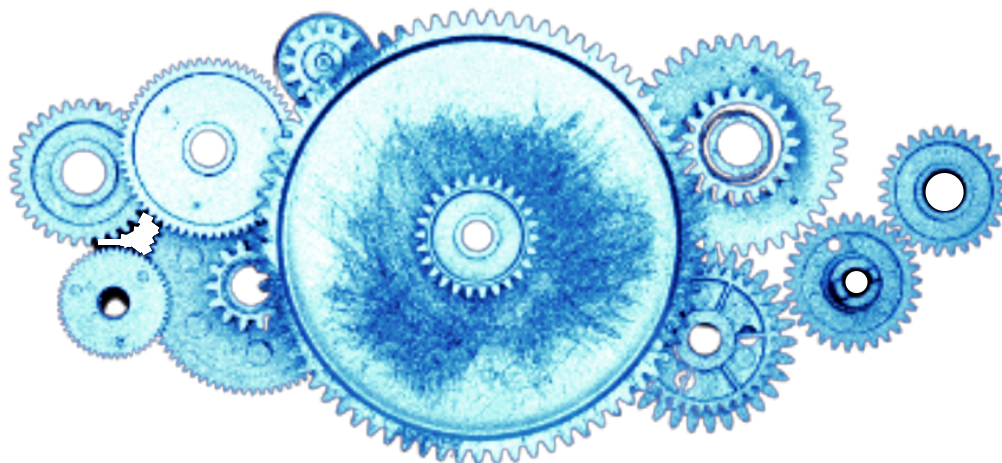
“I think when lockdown happened it’s about how do you be creative and use initiative and how to use everyone’s experiences to get everyone’s voice out there because there is digital exclusion and digital exclusion has always been there... Where do we use our connection skills and our network to reach the voices who may not have digital connection?”

Of course, online engagement was not part of the original plan for most, and the social element of face to face meetings was missed by many. One programme lead felt the programme “lacked something” because of the shift to a digital platform, but was unable to explain fully what she thought this was. Yet, when speaking to a beneficiary of the same programme, he explained:

“We were lucky as the first meeting had happened already – face to face. We had already met each other. And yes, while it’s nice to meet up, we had a WhatsApp group which meant we could do the informal bits as well as the formal, but in different ways. We even had tea breaks while on Zoom. I think it encouraged us to work harder on the programme, as there was no travelling, less chatter in the sessions.”

We heard how the programme provided well needed optimism and hope in a difficult time, evidencing the value of these community focused organisations in combatting isolation.

“I was shielding and never saw no-one, but going on zoom every week and having our WhatsApp group to turn to every day was amazing as it made me focus on my future. COVID made us bond even more than we already did ‘cause of our shared experiences but I think it made us also knuckle down so to speak and that quiet was good for us, but only because we had the programme. If we hadn’t, God knows how the quiet would have affected our minds.”



Successes

There is much to celebrate in relation to this funding programme and we touch on a few points within this section, including the reach of the fund in terms of number of beneficiaries, the developing skill set, sustainability and systems change.

Number of beneficiaries

No organisation reported any problem engaging with service-users or communities, or attracting LEx leadership candidates. Likewise, no issue arose around the engagement, participation and retention of participants in the programme, refuting commonly held assumptions and notions of “hard to reach communities” or a lack of interest in leadership development. Inclusion London found the quality of the applicants to be exceptionally high, leading to challenges in shortlisting and selection. Both the Muslim Women’s Council in Bradford and Inclusion London exceeded their intended quota of 12 participants (each), eventually recruiting 30 women and 19 leaders respectively.

Collectively, the organisations estimated that the fund had benefited 408 direct beneficiaries through leadership programmes and mentoring opportunities. Further, through those who provided estimates of their indirect beneficiaries too, it was thought to have reached as many as 1,268 direct and indirect

Organisation	Beneficiaries		
	Direct	Indirect	Total
4 Front Project	30	30	60
The Care Leaders	20	200/300*	520
WITH	12		12
BAC-IN	10	50	60
Sour Lemons	12	4	16
Comics Youth	20		20
Sub-Sahara Advisory Panel	20		20
Scottish Recovery Consortium	80		80
ALLFIE	14		14
Emerging Futures	20		20
Inclusion London	10		10
CLI	1	44	45
Action on Postpartum Psychosis	3	83	86
Inclusion Scotland	12	12	24
Migrant Centre NI	11	21	32
Kinfolk	26	13	39
User Voice	40		40
Muslim Women's Council	30		30
Inclusion North	7	16	23
Girl Dreamer	30	100.	130
Total			1281

beneficiaries at the one year point of the project.⁶ However, some found it difficult to estimate indirect beneficiaries, stating, “**It would be impossible to imagine the impact**”. A full breakdown of direct and indirect beneficiary estimates is presented in the table above.

[6] These questions were asked of organisations in initial interview; however, two organisations did not attend and thus this information was taken from their application form.

Skills and qualities

We observed the development of new skillsets across the programme. However, importantly, grantees were keen to stress that programme participants were already skilled and ready at the time of the project initiation, but were not aware of their own potential. One partner told us: “Imposter Syndrome is massive with this group; they seek to minimise themselves, so our job is to build them up”. Another said:

“Activists by their very nature have tremendous strengths of character and already have leadership skills that help them to influence, challenge and support work that public services and others do. They are the blood of the sector but are often unrecognised and undervalued.”

Inclusion London explained:

"Society positions disabled people in a convenient narrative. Organisations, who are not LEx led, will use the “aw poor thing” method for fundraising and this has pigeon holed disabled people into society believing they need to be pitied. Either that or they play a villain in a film. When instead, all those leadership qualities are there. Why wouldn't they be? It's changing the narrative so that disabled people don't have that as an additional and totally unnecessary further barrier to their autonomy and success.”

Owing to their own lived experience and success in leadership, the LEx leaders in this cohort were working to emphasise strengths and disrupt societal structures that, not only, practically prohibit LEx leaders from progressing but psychologically prohibit too. Having a safe space in which to self-reflect enabled recognition of barriers being externally imposed, rather than resulting from any personal failing.

“Do not be defined by your label. You are not an item you are a person.”

“One [challenge] was how hard it was initially for our participants to move from ideas to action after lifetimes of being denied real choice, control and power. We overcame that through coaching, peer support, to dive deep into the impact of discrimination and lack of control on people's skills, confidence and ability to take action, signposting to other training and support, and experimenting with different kinds of access support to enable people to take action independently.”

“[We are] humbled by G's willingness to use coaching to think very deeply and honestly about barriers she has faced to leadership. Looking forward to seeing if her 'change experiments' help her to build confidence and self-belief.”

We noted how a psychological shift took shape and how the beneficiaries were redefining their own aspirations and pushing their own, and society's, boundaries.

“All participants have gained confidence in their ability to become leaders in their own rights. Some have disclosed their aspirations of starting their own organisations to give back to their communities, i.e. set up support networks for people leaving care and set up rehab facilities led by people with lived experience.”

“Congratulations to “B” who got a funding application submitted – she’d been working on it for a while and putting off submitting, but she used support from her peer group to overcome her worries, and coaching support to finish off the bid... and she has just heard it has been successful! No stopping “B” now with her plans for more participatory arts projects led by Disabled people in West London, and great collaborative working with local DPOs.”

A huge impact was made by LEx leaders at WITH, whose initial centre in Wales has been adopted by the very women who transitioned through the leadership programme, with the founder (herself a LEx leader) acquiring additional space and leaving it in their care.

“The women that we train are going out into the community and making positive impact. They are setting up their own centres or working and volunteering at existing centre. They are even taking their transferable skills out into other sectors. In our area alone, WITH used to be the only service of its kind but there are now 4 other therapeutic horsemanship centres either up and running or in the process of setting up, all staffed by our trainees!”

Some leaders gained new and additional skills, including new digital skills. The pandemic forced the hand of both the pilot partners and the beneficiaries to take a lesser known path, resulting in unexpected positives. One organisation stated the pandemic had challenged them to consider their existing business models and how evolving through digital methods could enable them to meet more needs and engage more people, particularly in rural areas, at a lowest cost.

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“As we have all become more zoom literate this has probably increased, rather than decreased, participation.”

Another partner described a number of benefits gained as a result of the pandemic which can continue to be applied in the future, within the grantee organisations and beyond. She explained how online engagement has become another tool in the toolkit and should continue to be developed beyond the pandemic.

“People are coming online who would not go outside the front door because they can’t. It offers another way for people to engage. They can retain their anonymity, you don’t have to show your face, you don’t have to use your name, so equally we can learn from the past. I think we can learn a lot from what’s going on now to offer a wider access to people. The second thing that I find really interesting is that the power dynamic really shifts when you

are not having to go into a government building into a government meeting room and it's not your space, so what I found is it's a much more shared space online because the power differentials are quite different and I have also found that the fact that someone's cat will walk past or their dog will walk past or their kids will come in has actually humanised a lot of people I was actually quite scared of and actually in terms of lived experience in its broader sense, going online has given me a picture of what people are really like, not their professional selves, which has been fascinating."

Further, some of the more traditional leadership skills of budgeting and/or project management were being refined in groups, especially where leaders were able to move beyond initial reservations surrounding leadership and identify which skills would enable them in the future. It was notable how many were using the programme as a springboard to subsequently seek further training and development opportunities.

"BH has made great use of her training budget from the programme. She has enrolled on a Sheila McKechnie Foundation Influencing Change London course, to learn more advanced campaigns skills. She is finding it really helpful, particularly the support to work through a particular campaign, and the inspirational talks from successful campaigners."

Sustainability and growth

LEx organisations are brimming with energy, ideas and visions for change. Many responses received throughout the learning journey concerned what should happen next organisationally; innovations to plug gaps and reimagine the new were plentiful. Suggestions included developing phone apps to reach those even more socially excluded or disadvantaged; or building new and targeted campaigns to address social injustices unseen by the broader social sector and civil society.

Some of the programmes required leaders to generate their own change programmes in the community, further broadening impact.

"7 out of the 9 leaders on the programme made massive strides in development of leadership good practice and confidence... and several set up new services and initiatives that will have much wider benefits for our community."

"We are also going to develop a phase 2 framework which is a solid way of developing young women of colour and utilising their lived experiences to create more community role models and lasting change in local communities with these young women at the forefront of this social change. This will become available as a free resource to our community."

We spoke to direct beneficiaries of some organisations; people who had attended and completed the leadership programmes. We heard examples of how they had directly influenced their own organisations, which had enabled teams to work in bolder, more socially focused, ways. Some beneficiaries have since gone on to set up their own businesses. One such beneficiary we spoke to had previously been long term unemployed due to living with a disability while the others had always been in employment that was unfulfilling. The potential for creating social mobility and addressing economic injustice

within the social sector felt exciting to them and inspired them to reconsider their options. One leader who attended the Sub-Saharan Advisory Panel leadership programme was able to influence change within a large national charity, specifically in relation to the Black Lives Matter movement of 2020.

Care Leaders has been able to garner the interest of over 56 local authorities, who are actively considering sending care leavers and participation workers on the fellowship programme in the future, ensuring sustainability beyond the TNCLF grant awarded.

Important for sustainability was the need for increased visibility, representation and connection. Inclusion North recognised the lack of visibility of their organisation as a matter to be attended to: “The project will potentially bring more publicity to the organisation and our vision”.

The Muslim Women’s Council had struggled, until this programme, to access funding to support their work and the leadership development of Muslim women. However, since securing funding from TNCLF, their organisational confidence has risen and the LEx leadership framework has helped them secure further funding, enhancing the understanding of local funders of the value and importance of LEx leadership.

Several organisations in the pilot programme went on to receive subsequent continuation funding from TNCLF and other funders. It is clear the fund has acted as a springboard for certain organisations in terms of sustainability and growth.

Clear evidence has also arisen of impact at a system level, although this warrants further exploration in time as impact appears to become more significant as grants come to an end. Organisations

reported that this success was founded in access, visibility, scaffolding and, more importantly, the time and space to do such work. Some of the successes included LEx leaders holding a senior advisory role to the Ministry of Justice and another holding a co-chair position of a national BAME working group run by Vision UK. Two organisations, the Scottish Recovery Consortium and Sub-Saharan Advisory Panel, have been directly consulted by their respective governments regarding policies related to how best support their communities.

“The “real life” visible examples of successful leaders with lived experience will provide confidence in others to untighten the cap on the opportunities provided for those who may not have such a strong academic or professional background; and to appreciate that all life experiences have something to contribute to the success of a person’s future who is driven to succeed.”

APP were able to influence activity through involvement in internal NHS England boards on perinatal mental health, and in particular BAME perinatal mental health, and by raising awareness of the issue at Peer Fest in 2019. Additionally, they secured a workshop at an academic conference to present on their model and practice.

“Our National Training Coordinator delivers Lived Experience talks and Workforce training in PP to health professionals across the UK. Feedback from these professionals clearly shows the importance and impact of receiving training from a Lived Experience leader.”

“We are so grateful to the National Lottery for this innovative programme, supporting organisations to develop Lived Experience Leadership and develop as gold standard Lived Experience employers.”

Limitations

Firstly, it is important to acknowledge that the pilot phase took place during one of the most turbulent periods in modern history. The COVID-19 pandemic necessitated significant modification of our methodology and proposed timelines, just as changes were made at project level. We circulated our Learning Capture forms as intended, with an acknowledgement of the challenges facing the cohort, a “round-up” of potentially useful resources, and a separate form regarding how they were experiencing and managing the COVID-19 lockdown. Some partners requested virtual meetings or telephone calls to discuss their experiences in place of completing the forms, while others completed multiple forms, again cementing the individuality of each organisation. Some partners did not engage with us at all about their learning and reflections.

In addition, the varying project durations presented some challenges to the coherency of the learning analysis. Some projects (Kinfolk for instance) had completed or near complete their project activities by the time the learning partner contract was awarded. Further, not all projects commenced at the same time, presenting further challenges with comparative analysis.

Relatedly, the partners were not funded to attend learning partner events or complete learning capture forms. Grantee partners were keen to meet with other programme organisations but funding for time and travel to attend cohort learning meetings proved challenging for many. Further, at a time when resources were stretched, reflection and learning were not a priority for most as their time was consumed responding to their own challenges to ensure the continuation of the projects. This has been addressed in the second wave of the fund, where grantees are able to use part of an “uplift grant”⁷ to work with the learning partner, which has vastly changed the level of involvement. Organisations suggested that the cost for this be factored into future programmes.

Some of the initial questions posed by TNLCF have therefore rolled over into the second wave of the funding, and are being asked of the newest cohort of grant holders.

Despite challenges, we found the pandemic did not dull the spirit of the cohort and the passion, drive and love of the LEx leaders, and this was a clear feature of our work. However, a downside to this was the risk of burnout, although partners were largely keen to continue.

“LEx work has got a personal purpose for everyone who’s involved. It’s questionable how healthy the commitment is. You give everything...”

“It’s just horrendous so my work is 18 hours but that’s not enough. I am out there as often as I can.”

“As a lex leader you give so much of yourself that you don’t protect anything of yourself and you don’t take a break because if you do work just backs up, so you just carry on.”

[7] The uplift grant is to be used to increase accessibility as well as engage with the learning partner.

One organisation had reflected on the work/life balance and put in place measures to combat its impact in the future for their teams.

“One of our new organisation qualities is self-leadership, being able to maintain a positive work, life balance. Will recruit on the basis that people can maintain this. We’re not heroes, we need to stay somewhat healthy ourselves to continue to do good work with others, if not we’re useless.”

We also note that only four organisations had planned evaluations/formal external reports reflecting on their work and impact and we question whether this lack of reflection and evaluation might hamper developmental, project learning and leadership progression; as there is no ability to measure what has worked and what has not.

Some organisations have suggested to TNCLF that future funding rounds could encourage organisations to budget for an evaluation of their projects or extend the role of the Learning Partner to offer this function to individual projects. One grantee stated that they needed advice to understand how evaluation might work within their organisation and the benefits of this.

Where do we go from here?

We asked grantees to consider the following questions:

- What should TNCLF's strategy or approach to Lived Experience Leadership be in the long term?
- How should TNCLF be supporting lived experience leaders and their organisations, both in set funding programmes and their wider work?

Organisations were very engaged with this question and it elicited plentiful and extensive responses; they wanted TNCLF to develop their ambition to “put people in the lead” by building on the learning of the pilot programme.

They suggested the following elements as being important to a LEx leadership fund:

- Maintaining ease of applications, and providing guidance on who is and who is not entitled to funding.
- TNCLF should create an archive of programme learning and outcomes that would be accessible to prospective applicants, so that TNCLF were not continuously “reinventing the wheel”, and by so doing were acting to spread learning within the LEx Movement about methodologies and approaches.
- A communication strategy should be attached to all work developed through the Lived Experience Leadership programme. Promote this model of working far and wide!
- TNCLF should continue to support the building of LEx Networks and communities of practice, recognising the power in creating networks or communities of shared interest. We would suggest that something like LEx Movement could take a proactive role (alongside TNCLF) in bringing current grantee partners and new partners together to connect, support each other and share learning, and to begin to build a recognised network of Lived Experience Leaders.

- Provide support to evidence work undertaken, through evaluation workshops or funding.
- Maintain the uplift grant to offer teams the space in which to reflect on their learning journey.
- Continuing to increase the size of the grant and the duration of funding was suggested by several respondents, so as to allow the organisations to fully focus.

Since the pilot programme, TNLCF has released more funding to LEx leaders; 49 more organisations have been funded up to £50,000 for up to two years, to promote LEx leadership within their organisations and communities. It was promising to see members of the pilot fund community advising on the applications and forming a central role in the decision-making process. Again, LEx has been centre stage.

As EP:IC continue to collect information as a learning partner for the next wave of the funding programme, we have been able to more systematically explore the principal questions of TNLCF:

- What does good LEx leadership look like?
- Under what conditions can LEx leadership thrive?
- What can funders do to enable and support LEx leaders?

However, we also take forward some of the learning and new questions that have arisen from the pilot. For example:

- Exploring the definition of LEx leadership more closely, including the distinction between lived and living experiences.
- What are the challenges in relation to disclosure of LEx, and the right to privacy?
- Shining a light more directly on the journey of beneficiaries.
- Consider in more detail the leadership training methodologies of the grantees.
- Reflecting on the systems change work that is happening as a direct result of this important LEx leadership fund.

It's evident the fund has made an enormous difference to not only the organisations that participated but also to their respective communities. At times there have even been some unintentional and unexpected successes despite the challenges that every organisation faced in delivering their projects.

Importantly this fund has helped to position LEx leadership awards as central to wider funding opportunities. It has helped combat the disadvantage and stigma felt by lived experiences in leadership; and recognises how lived experiences are strengths and not weakness in organisations, communities and wider society.

In many instances the fund has given organisations the space and resources to test, strengthen, and grow, both internally and externally; and help wider society recognise the unique and essential role LEx Leadership can offer to individual and system change. It is a mark of recognition and success that the overall 'reach' of the grant might be immeasurable; and long after the grant has ended, the impact of it continues to be felt by those involved.

Action on Postpartum Psychosis (APP)



APP's workstreams are led by programme leaders who each have lived experience of postpartum psychosis. These leaders oversee teams of staff and volunteers with lived experience: delivering peer support; training health professionals throughout the UK; and supporting work to improve regional services.

The Postpartum Psychosis Lived Experience Leaders project aimed to: provide additional training and support to our national programme leaders; provide benefits to ensure that lived experience leadership is sustainable; relieve burdens on programme leaders, and improve succession planning, by training an assistant coordinator to provide contract cover during weekends, holidays and periods of sick leave.

The project helped our staff to develop as vocal lived experience leaders and enabled APP to pilot gold standard ways of supporting and sustaining lived experience leadership, informing our future work, and championing lived experience at all levels within our charity.

Why Lived Experience leadership matters:

Action on Postpartum Psychosis (APP) is the UK charity dedicated to supporting women and families affected by postpartum psychosis (PP). Founded in 2010 as a collaboration between women and families with lived experience, world leading academic researchers and expert health professionals, we work to address stigma and provide life-changing support.

Of our 26 staff, 22 have personal experience of postpartum psychosis. Our Trustee Board is an equal mix of women with lived experience of PP, academics and clinicians. This collaboration is the heart of all our work, resulting in values-led, safe, high-quality services that are informed, accessible, empathetic, and meet real need.

Our key workstreams (peer support; NHS partnerships; health professional training; research and information; awareness raising; and campaigning) are led by National Coordinators with lived experience who oversee teams of staff and volunteers. APP is passionate about the benefits of lived experience leadership and about sharing and learning from best practice. We aim to be a gold standard mental health lived experience employer and women's organisation with family friendly working practices. We were delighted to be selected for wave 1 of TNLCF Lex leadership fund programme. We used the support of the project to further invest in our National Coordinators' leadership and management skills. Building on these skills means we can deliver better quality programmes and services for the women and families we support.

Our National Coordinators have seen their roles and responsibilities grow and evolve; they have each at least doubled the number of volunteers for whom they are responsible, and all now manage their own staff and projects. Training in leadership, project planning, managing staff, managing volunteers, presentation skills and time management have all been hugely beneficial for them. We also used our Lived Experience Leadership funding to

trial and implement innovative strategies to support our organisational development as a model lived experience employer. We trialled: coaching and/or counselling sessions for our Lived Experience Coordinators; co-working days, and flexible working.

We examined support and training across the organisation; and conducted a piece of work to ensure that no critical functions rely solely on any one individual. It is important to us that all staff feel well supported by peers as well as supervisors, and able to share work with others during holidays, at times of sickness or family responsibility. We developed and implemented tailored Wellbeing Plans for all staff.

We conducted a piece of work researching working conditions that inadvertently cause gender and mental health inequalities, setting out a development plan for the organisation. We implemented a staff income protection plan to support staff who are unable to work after eight weeks of sickness for up to two years – ensuring that long term sickness does not add financial difficulties to an already stressful family situation, whilst ensuring that the charity can continue to function and cover workload.

Much of the value of this work was demonstrated during the early months of the coronavirus pandemic. As most of our staff and volunteers have a history of psychosis or bipolar disorder, we understood the need to minimise stress during the lockdown. One of the first approaches we took when adapting to the pandemic was to ensure staff were able to adapt their working patterns to suit their specific needs, for example around home-schooling, reducing hours where possible.

We identified critical operations, new operations needed to manage risk in our population, and work that could be delayed. Having ‘been there’ themselves, our staff and volunteers understood better than anyone the lack of support and isolation our service users were facing during the pandemic, and the risks this posed. This led to them working hard, but flexibly, to continue providing peer support and information; adapting services, replacing face to face contact with video calls, emails and virtual meetups; outreaching to the highest risk populations; and increasing our use of social media. We set up staff and volunteer-run online activities such as crafting, exercise classes and baking to reduce isolation and promote self-care and wellbeing. Our work ensuring adequate holiday and sickness cover for all essential operations proved crucial in maintaining our functioning during this time. Staff pulled together and supported each other to manage illness, stresses and individual family circumstances – ensuring that pregnant and postpartum women and families were still supported and could still access lifesaving information and support.

By setting the example of gold-standard lived experience leadership in this way, organisations like APP can help to affect sustainable change across the third and social sectors. Recent years have seen a growing interest in the benefits of lived experience leadership. We work collaboratively with charities and other third sector organisations and share best practice in support for lived experience leaders with them. APP builds time into staff schedules to enable staff to attend events where they can talk to other charities, not for profit groups and the NHS about their roles as well as raise awareness of how lived experience leadership can positively impact stakeholders and beneficiaries.

This is of particular importance for organisations working in the field of maternal mental

health, which has been highlighted nationally as a key development area – where input from the lived experience voice is crucial. We believe APP is an unusual organisation given the proportion of board members and staff with lived experience and is an example of how those with lived experience, academics and health professionals can work together to improve the future for patients. We would like to see much more work and investment in these types of lived experience communities, supporting the development and promotion of the lived experience voice to the general public, NHS, in universities and to policy makers. Our own experience proves just how valuable it is and the benefits of championing lived experience at all levels of an organisation.

As one APP community member said: “I have found the whole thing therapeutic and I'm ready to support others in need of help. APP saved my life. I'm ready to give back and hopefully save more lives with the support of APP peer mentor staff.”

Inclusion London

Developing Deaf and Disabled Leaders for the Future An 18-month prototype leadership programme for Deaf/Disabled leaders, borrowing from ideas of “collaborative leadership” and a “human-centered design” approaches to change management. 9 Deaf/Disabled people from London DDPOs actively built leadership skills and confidence through leading a real change on issues they were passionate about, with coaching and peer support to explore ideas and solutions, understand and get past barriers, and reflect during the journey.



Writer's role in the project: Project lead

Writer's role in the project: Project lead and coach Step into any DDPO (organisations led and run by Deaf/Disabled people) and you will be greeted by an incredibly diverse and talented group of staff, trustees, volunteers and members. Lived experience brings passion for change, and potential for unique and creative approaches, but all too often Deaf/Disabled people's leadership potential is not realized because of multiple barriers and discrimination. In true Disabled People's Rights Movement style, we decided to take a “Nothing about us, Without Us” approach to this problem.

Who better to design an effective leadership programme for Deaf/Disabled people than people with lived experience? We started with a prototype design, drawn up after focus groups with existing Deaf/Disabled leaders, and used a “test and learn” approach with 9 Deaf/Disabled people, nominated by London DDPOs. They came onto the 18-month programme to explore their own leadership journeys whilst helping us codesign even better programmes for the future. DDPOs told us their definition of leadership is “Someone who makes change happen and has influence or decision-making power in areas they are passionate about.”

We wanted to test the idea that Deaf/Disabled people can find their own creative ways to strong leadership (not necessarily in traditional roles) by learning through action. We would enable people to lead real change on something they are passionate about – with light touch training on change management, followed by coaching and peer support to explore

ideas and solutions, understand and get past barriers, and reflect during the journey. It was a rollercoaster ride as we navigated our way through an experimental programme which encouraged people to follow their passions, take risks, and challenge societal barriers, all whilst managing change during a pandemic! The highs outweighed the lows and the impact for individual leaders was impressive. We proved that learning through action is powerful. Working on practical projects allowed leaders to move from passion to action and through to confidence and self-belief. We learned a lot about what is important in a leadership programme for Deaf/Disabled people thanks to the generous self reflections of the leaders.

Human-centred design approaches were helpful for managing change. The emphasis on developing empathy with people you are designing solutions for; valuing diverse perspectives and unusual ideas; and learning through risk taking and experimentation, tailored well with leadership skills development. Leadership skills that improved most during the programme were having a strong vision for change; resilience and adaptability; and being able to encourage curiosity and debate.

"I learnt that I am capable of leading change and making positive things happen. I learnt the importance of maintaining continuity and not giving up." Most leaders found it very helpful to have a Change Canvas to guide their projects "It helped me stay on track and if I felt stuck it reminded me of the different ways at looking at the change process."

Using design based problem-solving techniques (adapted for access needs) was helpful in encouraging flexibility, which some leaders feel they have taken into their wider lives. Design tools also helped us improve the programme itself. Leadership programmes, or indeed any training and development opportunities, rarely consider access needs, or only focus on well-known needs such as wheelchair access or hearing loops.

This programme went much deeper and showed that people succeed when access needs are genuinely met. During the first workshop, leaders learned about the "design cycle" and tools for developing empathy, by codesigning a learning environment suitable for everyone on the programme. That set the tone for the rest of the programme – support and adjustments were varied and flexible. Every time a leader got "stuck" with a goal it was seen as an opportunity to understand societal or impairment related barriers and creatively explore solutions. For some leaders this was the first ever opportunity to experiment with support and adjustments.

"The programme gave me the safe place to explore, and tools to be able to grow as a person in this area. This is the first time I haven't had to tell people what I need."

Empathy-building meant leaders were in tune with others' diverse needs and perspectives. They enthusiastically took that approach into individual change projects, and it was also a powerful element in creating a safe and brave learning space. Leaders so valued the peer learning group that they have chosen to continue it to this day. A crucial success element is the programme's rights-based and Social Model of disability frame. Leaders found learning with other Deaf/Disabled people helpful in itself: **"Having a shared background is so important. You can jump over the tedious basic stuff and get straight to the core of the issue."** The heavy focus on unpicking societal barriers is what several leaders pinpoint as

making the programme unique.

"This programme really was focused on the root of the issue and disability and leadership: what has really prevented us up to this point and a safe place to really challenge this and maybe find some breakthroughs."

Monthly coaching was provided by a neurodivergent coach with lengthy experience working within rights and Social Model focused organisations. The emphasis was on promoting self-reliance and maintaining power and decision making with leaders "We had a coach who didn't tell us what to do. They helped us work together as Disabled people on barriers that stop us being our best, how that made us unconfident, and how to change that." We gradually saw increasing assertiveness in being heard and requesting reasonable adjustments, and development of more positive self-identity.

"Together we opened up and were able to start looking for solutions, facing the things we had struggled to address or identify. It was a fundamental conversation that I was ready to have due to this programme."

For some, this involved a deeply personal journey of working through traumatic histories of oppression or years of masking difference. It was wonderful to see a growing desire to be fully seen, and increasing pride in how lived experience contributes to leadership: "I'm not hiding anymore. I made an interesting personal discovery. I realized that my lived experience of disability gave me an advantage. There are acquired skills I overlook as I see them as a way of life."

And with flexible signposting to other opportunities and encouragement for experimentation, leaders racked up an impressive range of new practical skills they weren't expecting to gain from the programme. It's hard to decide which standout successes to pinpoint because there have been so many, and we are continuing to see leaders go from strength to strength.

We have seen leaders develop in traditional leadership roles such as committee Chairs and trustees or taking on more senior job roles; new partnerships have been forged across DDPOs as leaders collaborate on a range of initiatives that use leadership skills in more fluid ways; and several leaders have taken on mentoring and coaching roles in their areas of interest.

No programme is without its challenges. Perhaps the greatest is that supporting Deaf/Disabled leaders to develop skills, pride and ambition, and equipping them to more easily recognize and challenge societal barriers, doesn't actually take those barriers away. Leaders tell us about their continued frustrations and setbacks as they are underestimated or denied access to opportunities despite their achievements.

There's a long way still to go, and a lot more investment needed to really open up leadership to Deaf/Disabled leaders with a passion for effecting social change. It was brilliant to be able to try out this prototype programme through the NLCF Lived Experience Leadership funding initiative. We have been hugely excited by this great start, but one of the frustrations was lack of an immediate route within the initiative for consolidating and

scaling up success.

We have been lucky to be able to engage with Camden Disability Action to run an adapted programme from 2020-2022, this time testing out its effectiveness with a cohort of 12 Disabled Camden residents, more marginalized from traditional leadership positions than the original cohort. It has been brilliant to see the same changes in leadership practice and an even broader range of unexpected benefits.

Leaders have achieved more active engagement in the community, new social as well as professional networks, and started a range of new user led services for the community. Several of the first cohort contributed to this success: sharing learning, taking on mentoring roles and one becoming a coach on the new programme. But despite the out and out success of the programme we are now back to the same position of seeking funding for continuation.

This is an approach clearly worth investing in and we are excited about its future. As graduates from both programmes say... **“There is so much potential floating around your DDPO. It is important that you start tapping into this potential!”**

“Nobody told us to think big before. We don’t want to stop now!”

Inclusion North CIC



Bringing Change to the Board! The project was based on the belief that people with a learning disability or autistic people can and should be directors or trustees within organisations. It was about supporting and developing inclusive governance.

Our aim was to build the confidence and knowledge of people with lived experience to become directors or trustees. To strengthen organisations through this diversity and inspire others to bring this change. The project was designed and delivered with 2 Lived Experience Leaders employed as Leadership Coaches.

Inclusion North values the knowledge, experience, and skills Lived Experience Leaders bring to the work we do and have actively sought this involvement in our projects for a long time. We are led by an inclusive Board.

What we realised from the project was just how scarce the training and support is for people with a learning disability or autistic people in relation to inclusive governance, and for organisations looking to establish this.

Our experience as an organisation with an inclusive Board was hugely valuable and identified that we are among a small collective of organisations leading the way in this practice. The funding enabled us to create employment opportunities, different to those we already had in place for Lived Experience Leaders.

The Leadership Coaches employed became core members of the wider project delivery team at Inclusion North. The experience and success of the project has been referred to in

subsequent funding applications we have made. We believe this has significantly helped secure additional funding and therefore continues to contribute to the opportunities that have arisen from this. The power of peer learning and support, both amongst the project participants and the project team, was significant and something we had not anticipated.

Everyone's contributions were unique, people really brought something of their own to this. This sharing proved really powerful. The Lived Experience Leaders who co-designed and delivered the project identified the following personal outcomes.

- **Skills** – research, presentations, computer, development of resources, team working, use of Apps, reading and writing, contingency planning.
- **Knowledge** – understanding of inclusive governance, including legal aspects.
- **Experience** – gained confidence, connection with the wider organisation, a feeling of being valued, treated equally. How training and support works best for them as individuals. Inspired to look for other opportunities and appreciation of seeing others progress and gain confidence.

There are many things to celebrate from this project including: • Three people with lived experience who participated have gone onto secure director or trustee roles. • Both Leadership Coaches continue to be employed at Inclusion North and are working on the development and delivery of three new leadership courses over a 3 year period. • The work of the project team was 'highly commended' at the Disability Smart Awards 2021 in the Disability Smart Communications category.

This Communications Award recognises organisations or teams that have created truly inclusive and accessible communications for disabled people. • The resources produced from the project remain freely available to individuals and organisations on the Inclusion North website

https://inclusionnorth.org/our_work/bringingchangetotheboard-inclusivegovernance/

The project faced significant challenges because of Covid and the related lockdowns, none of which could have been predicted. This resulted in the Leadership Coaches working in isolation at home, becoming wholly reliant on technology to connect for work, and having to redesign all the training and resources to fit with online delivery. Furlough was also a factor for both Leadership Coaches causing uncertainty and inconsistency.

This was addressed with positivity, determination and exceptionally good team working. The passion and drive with which the Lived Experience Leaders had started the project was quick to return. Flexibility and some additional funding from the Lottery helped make the difficulties encountered more manageable. This funding provided a brilliant opportunity for Lived Experience Leaders to demonstrate what they know and can do.

The delivery of any project will be enhanced by this involvement. Lived Experience Leaders gain valuable skills, knowledge, and experience, with the connections built utilised to enhance other opportunities. It encourages Lived Experience Leaders and organisations to be ambitious and in doing so evidence the value in equality, diversity, and innovation. Inclusion North exists to make inclusion a reality for all people with a learning disability, autistic people, and their families. This funding opportunity fitted perfectly with our values.

Beneficiary feedback: Participant 1

Has the LEL project had an impact on your life?

It has had a hugely beneficial impact on my life, giving me the confidence and self-belief to speak up and to use my Lived-experience as a late-diagnosed autistic stroke survivor in a positive and empowering way.

What did you learn about lived experience leadership as result of the project?

I learned that Lived-experience leadership can have a profound effect on both the lived-experience leader and the people with whom they work. Using real lived experience, coupled with the shared vulnerability which that brings, allows both sides to grow in understanding. It encourages people to bring their own truth and experience to a conversation or a project, to begin to learn how to support each other better, and to eschew competitiveness in a combative sense.

What have you been doing since the project ended?

I found the experience of speaking with Anna Fowlie, CEO of the SCVO (www.scvo.scot), instrumental in my decision to apply for a Board position within a charity: Anna encouraged me to believe in myself and to use my skills and I will always be grateful to her for that gentle push! I am now delighted to say that I am the Scottish Trustee for the charity, Contact (<https://www.contact.org.uk>) which supports families with disabled children. I am thrilled to be able to bring my own lived experience as an autistic person, a Carer, and as a professional who has worked in the Third Sector, in education, and in the private sector, to be of service to others in this way.

Without the generous funding of the Scottish Government and Inclusion Scotland, and the nudging of Anna Fowlie, I do not think that I would have ever had the confidence to follow this path. Since 'retiring' after my stroke in 2019, and completing the LEL course, I have had the confidence to work freelance and to accept projects which I can take at my own pace. Anna Fowlie also persuaded me to charge for my work: until then, I had been taking on an awful lot of unpaid and voluntary work! I still do that, but now the balance is more equitable!

I am a Member of the Autism Advisory Forum working with Bee Vellacott and the team at Inspiring Scotland to inform the Scottish Government about Autism and taking part in the Different Minds Campaign (www.differentminds.org) and the Access to Mental Health Services research project; I have designed and co-delivered two peer support programmes for autistic adults and parent carers with Kabie Brook from ARGH (www.arghighland.co.uk) in 2020-21; I was approached and designed and delivered research and a report on Equality, Diversity, and Inclusion (EDI) for the Royal Botanic Garden Edinburgh (www.rbge.org.uk)- in 2020-21; I was a guest speaker on EDI/Autism at the invitation of Pamela Nicol-Littlejohn at Ore Catapult (<https://ore.catapult.org.uk>); I managed to speak to ninety-six members of staff at Catapult by Zoom - the joys of technology!

Thankfully, I thought we might have about seven people joining in so I was quite relaxed! I became a researcher and consultant for an Inclusive Heritage project for Dr Alix Powers-

Jones at NTS Hugh Miller's Birthplace and Museum, Cromarty and Katey Boal at the NTS Culloden Hub 2021/22; (<https://www.nts.org.uk/visit/places/hughmillers-birthplace>); I designed and delivered a training programme on Equality, Diversity, and Inclusion and Autism awareness with colleague, Zainib Hussain, for three National Trust for Scotland properties in the Highlands 2022;

Participant 2

Has the LEL project had an impact on your life?

LEL project had a great impact on my life. This project has been a very significant step towards my leadership journey. This has taught me how to be focussed, imaginative, leading a team by collaborative working and always giving credit to them, able to listen well and take on board new ideas. I am now more willing to experiment with the notion of "leadership at work"-see what works and what does not. I now have a greater willingness to not see things as simply black and white embracing the grey area.

What did you learn about lived experience leadership as result of the project?

All the participants in the LEL project tested out various opportunities which included coaching, shadowing, training courses, a learning group and peer support sessions. All participants had lived experience of disability and a desire to be leaders of disabled peoples' organisation with a view to protecting and promoting the rights of disabled people and eliminating discrimination disabled people face in every sphere of society.

This has been the greatest element of my learning from the LEL project. I have learnt how to be a good leader in order to collectively solve problems, learn together and achieve the aim and objective of the organisation. I have learnt how to be open and transparent, have a clear aim and vision of the organisation and collaborate not only within my own organisation but also between organisations.

The Open University Course, "Developing leadership practice in voluntary organisations" was extremely helpful in achieving my goal. I have also successfully completed the "Thinking Digitally" course which has improved my digital skills a lot. This course has made me immerse in a digital online environment which was a new kind of experience specially during the pandemic when the only way we could communicate was by virtual meetings using a variety of online digital tools. I also found it extremely useful to learn about how to make our web contents and documents accessible and how to abide by "Digital Accessibility Legislation".

This has been a "Learning by Doing" experience and we have all learnt from each other in a digital online environment. I have not only learnt but also translating into actions all my learnings in my professional and social life.

What have you been doing since the project ended? Since the project ended, I have joined Inclusion Scotland's board of directors.

We were also wondering if you be willing to help with disseminating our own report launch?

I will be very happy to help in any way I can.

WITH



The Leg Up Project

The Leg Up Project funded training, childcare and travel costs to enable women with lived experience of disadvantage to become therapeutic horsemanship practitioners.

At With Horses, we believe that horses are for everyone, not just the privileged few. The Leg Up Project was created to address inequalities in the equine assisted industry where training is expensive and, as a result, the life experiences of the practitioners don't necessarily reflect those of our clients. As an organisation led by people with lived experience of multiple disadvantages, we know that those who have overcome obstacles in life are uniquely qualified to help others.

During the life of the Leg Up project, we worked with 21 women in North Wales who had lived experience of poverty, unemployment, trauma, mental health issues and disability. As a result of the Leg Up project, 12 women have gained an OCN Credit4Learning Level 1 Assistant Practitioner qualification, 5 have gained a Level 2 Foundation Practitioner qualification, 4 have gained a Level 3 Advanced practitioner Qualification and one has gained a Level 4 practitioner mentor certificate. Three women have set up their own businesses in the therapeutic horsemanship industry, two of them in Wales and one in Sweden.

Of these, one was previously long term unemployed due to disability and the other two are single parents who worked minimum wage jobs as a cleaner and a waitress. Three additional women who were previously unemployed have found paid work as a result of gaining their qualification and a further five have begun volunteering in their community. In terms of personal impact, in house monitoring shows that 90% of participants felt their confidence has improved since taking part in the course, 83% reported increased communication skills and 68% felt they had gained transferable skills that they could use in any career.

Although we are an organisation that was set up and run by women with lived experience of multiple disadvantages, this funding gave us opportunities to learn more about lived experience leadership. As a staff team, we found that being unafraid to speak about our lived experience of overcoming disadvantage was key. Letting our lights shine gave others permission to do so. We would implore other lived experience leaders to do the same: have an awareness of your USP and don't be afraid to sell yourself. Network as much as possible, blow your own trumpet, be your own advocate.

We also realised that willingness to ask for help is vital for all lived experience leaders, being able to delegate and networking with other services in the area can help to lighten the load. Selfcare was hugely important for our team as we often heard things from our participants that resonated with our own experiences, which could be triggering. Many of the women we wanted to reach suffered from stigma and lack of expectation. Often even the professionals involved in their care felt that the idea of them gaining a qualification and paid employment was unrealistic.

They doubted our ability as women from disadvantaged backgrounds to lead this work. It was no wonder that the trainees themselves felt powerless and had low aspirations. We kept our motivation during the tough times by remembering why we do this. If you're a lived experience leader, don't let anyone make you feel like less than you are or doubt your ability to lead.

Your experiences mean that you are uniquely qualified for this work. A breakthrough moment for us came when we realised that we could fit training to the lives of the women rather than insisting that they fit into some pre-existing structure. In order to make space for the women we trained to succeed, we had to not only understand but eliminate every possible barrier. We listened to the concerns that women had about accessing training such as paying for course fees, transport, and childcare, and we factored all of this into our funding proposal.

We made sure that women had training mentors, we provided lifts, food and accommodation for training courses. We created online courses for women who couldn't make it to our venue. Each trainee had their own personalised training plan that took their needs, talents, and preferences into account. We met women where they were. We believed in them at every stage and advocated for them at every level.

As a result of this funding, we actually changed the structure and enhanced the sustainability of our organisation. We started as a charity totally reliant on grant funding and became a CIC selling resources and training to fund services for disadvantaged people. The Leg Up project enabled us to create a suite of OCN Credit 4 Learning accredited training courses and a range of curricula that are available to buy on Amazon. This has given us greater freedom to try new approaches and direct funds to where we know they are needed. Our refusal to limit ourselves or let others be limited resulted in the women who took part in the project being able to take over the running of our Welsh centre when we decided to open a new, larger centre in Scotland.

This came about when two of the women that trained under the Leg Up Project came to us with a proposal. They had both had aspirations to work with horses and help people for as long as they could remember but life had gotten in the way. Between them they had experienced single parenthood, poverty, mental health issues, abusive relationships, grief and loss. One of them said that these things used to be her Achilles heel, bringing her down every time she tried to move forward, but now she saw them as her 'Superpower', enabling her to help others going through the same issues.

As an organisation, we will be forever grateful for the National Lottery Lived Experience Leadership Fund. It enabled us to grow, evolve and become more sustainable. It helped our staff to feel that our experience was legitimate and valuable. More importantly, it gave 21 women who were being held back by the perception that their life experiences made them somehow inferior to open up new ways of thinking, earning a living and interacting with others. What we love most is that the effect is ongoing. The National Lottery enabled us to give women with lived experience of disadvantage a 'Leg up' into what can be an elitist industry and many of them have gone on to do the same, helping other people to achieve their aspirations.

Trainee Testimonial

“Getting a Leg Up training scholarship has had a much bigger impact on my life than I ever expected or even imagined at the time. It has given me lots of new things: new skills of course, but also new friends, a new outlook, new enthusiasm, new self image, new confidence and ultimately new hopes and plans. I have gone from being in a rather dark place where I couldn't even identify any dreams or wishes, to now actually having started working towards having my own donkey EAT business! “The program offers professional training and skills, in a relaxed, supportive and 'allowing' atmosphere, and being able to be around the horses is therapeutic in itself. Knowing that participants have different backgrounds and experiences, also makes it less intimidating. Having someone believe in me, when I wasn't really able to do so myself, made a huge difference in so many ways. Experiences and ' baggage' which I had seen as negative, a failure and something to be a bit ashamed of, now turned out to be something positive, even a strength, and the very reason that I was able to participate in the program at all. It does sound a bit cheesy, but it really has been a life-changing experience for me, and 18 months on, I still discover ways that it has had a positive impact on my life. 'Thank you' doesn't really cover it.”

Migrant Centre NI



Migrant Centre NI Lead AchieVe Aspire (LAVA) Project The Lava Project developed a cohort of 11 'upcoming' grassroots community leaders with lived experience of the UK immigration system through a skills audit, professional development training, workshop and project development and delivery mentorship, and grant writing mentorship and support. We consider this project to have been a resounding success in that our leaders indicated they gained confidence, knowledge, and tangible skills through their year in the cohort. Leaders who I met through the programme who were just getting their groups off the ground are now colleagues of mine in the migrant and ethnic minority advocacy and support sector.

Several of our leaders attained funding for their groups secured during the grant writing mentorship portion of our programme and several of their organisations are now funded through the Global Majority Fund, which MCNI administrates on behalf of Comic Relief and have applied to TNL's Northern Ireland BAME Pilot Programme. Our leaders also facilitated workshops developed during the programme and sat on our end of project 'Lived Experience Leadership' series panels alongside contemporaries who are leader in their field in England, Scotland, Wales, and the Republic of Ireland.

The greatest challenge we faced, as I anticipate you are hearing from many groups, was the switch to remote working during the COVID-19 pandemic. However, we were able to make the switch successfully and the LAVA cohort provided an important medium for networking and support as our Leaders responded to the lockdowns through their respective grassroots organisations.

We think there was a huge amount of value and learning in this programme and we would be keen to run another like it should funding become available.

Acknowledgements

Our thanks, as always, to;

Everyone who engaged in the consultation.

To every organisation who took the time out of their busy schedules to speak with us and reflect on their experience of the fund and of LEx leadership.

To the beneficiaries who took part in interviews voluntarily and willingly.

To TNLCF, for championing and investing in LEx leadership.

