

Engaging people with lived experience of severe and multiple disadvantage

By

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VOICE

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EXECUTIVE SUMMARY

Via desk based research, interviews, focus groups and workshops, User Voice and Shaping Our Lives have sought to provide a range of recommendations for LankellyChase based on examples of best practice of service user involvement across the United Kingdom. These recommendations are intended to help guide LankellyChase in its efforts to attract more people with experience of severe and multiple disadvantage to submit funding applications to the foundation, include more people with lived experience in their organisation and better incubate service user ideas and talents.

Recommendations are ordered into the three main areas that LankellyChase seeks to develop; *Organisational change*, *Funding* and *Systems Change*. The recommendations are summarised in a table in Appendix A.

In order to facilitate *Organisational Change*, it is recommended that LankellyChase agree a set of values about what they really mean by Service User Involvement, and how they envisage this involvement working at LankellyChase. In establishing this value set, we also recommend that attention is given to the way service users are integrated, so that they feel equal and central to the workings of LankellyChase. Particular consideration of the support needs of people with lived experience is needed, which may include peer-led support structures.

In terms of the recruitment of service users to LankellyChase, it was identified that this needs to be an inclusive process in itself, i.e. involve service users in decisions about recruitment. It is important to ensure that recruitment processes give sufficient attention to the unique qualities that lived experience brings, for example belief systems rather than taught qualifications and work experience.

With regards to its *funding*, it is recommended that service users are involved in the development of a more user-friendly process, particularly with regard to the language used. Peer support is recommended for bid writing through workshops, and/or real life examples online. It is proposed that LankellyChase starts to develop a network of funding providers to enable effective signposting for service users. This will eliminate the practice of changing project ideas in order to fit with funders' ideologies.

Importantly, we recommend that LankellyChase get closer to the people submitting the funding applications to better understand their skills and what has driven them to apply for funding. The potential of ‘funder days’, to give both funders and applicants the opportunity to meet a large number of new people in a reasonably short amount of time to discuss how they might work together.

And finally, LankellyChase is committed to working with individuals to facilitate *Systems Change*. We suggest that funding organisations at grassroots level is an important component if LankellyChase is to be successful in this mission. The funding of core costs to help organisations become stable and sustainable is also proposed.

Further, central to Systems Change is the empowerment of people with lived experience of multiple and severe disadvantage. This involves capacity building, to ensure this hugely under-represented group have the skills and self-confidence needed to succeed in senior positions. Only through capacity building can the playing field become more equal and the system will be able to change.

TABLE OF CONTENTS

Executive Summary.....	1
Table of Contents.....	3
Aims of the report.....	4
LankellyChase Foundation – the current position	5
Methodology.....	7
Findings	9
Organisational change	9
Values.....	9
Inclusion	12
Flexibility in approach	14
Funding	16
Language	16
Relationships.....	19
Systems change	21
Grass roots & core costs	21
Empowerment	23
Appendix A.....	26
Organisational change	26
Funding	26
Systems Change	27

AIMS OF THE REPORT

LankellyChase Foundation believes that systemic change is *necessary* if severe and multiple disadvantage is to be adequately tackled.

They also believe that change is not only *possible*, but more likely if those with lived experience lead the change process by implementing new, innovative and even radical ideas.

LankellyChase are committed to working towards Systems Change and have a Theory of Change which sets out how they think this can be achieved. Applicants must show how their idea can contribute to this if they are to secure funding.

They are currently seeking to develop a strategy to:

- Attract more people with experience of severe and multiple disadvantage to submit proposals to be funded by the foundation
- Enhance their workforce and board by increased inclusion of people with lived experience
- Better support and incubate service user ideas and talents

To assist in this mission, this report outlines noteworthy learning from existing user-led initiatives nationwide, both positive and negative, so that LankellyChase is better informed about the direction of its new strategy.

LANKELLYCHASE FOUNDATION – THE CURRENT POSITION

The current grants experience is designed to be open and accessible to all. All applicants are required to answer six initial questions relating to their project idea. They can be answered in a variety of formats, including in a video application, email, standard letter or telephone call. A registration form is also required. At this point, the idea is vetted in line with LankellyChase's Theory of Change to ensure that it is striving to achieve Systems Change, rather than provide a specific product or service. If an idea is deemed viable, then it will be developed alongside a director at LankellyChase before the final decision is made by trustees. Unsuccessful applicants are provided with notification that their idea will not be developed or funded, and have the opportunity to request detailed feedback. It is understood that approximately 95% of applications are rejected at the early stage because they are not affecting Systems Change but are providing short term 'sticking plaster' solutions. However, any projects which are user led are given more attention to establish the root of the idea and are not eliminated in the same way. This all happens within a six week period.

LankellyChase are not stagnant in their approach. Their thinking around service user involvement has evolved and will continue to evolve. However, this can only happen through learned experience. In the previous 18 months, we understand that out of the 480 proposals submitted to LankellyChase, only 25 (5%) were user led. LankellyChase recognised the need for a specific focus on this issue and therefore commissioned this work.

The Foundation has created the Promoting Change Network (PCN) to bring together individuals from organisations across the UK who are actively working to create the Systems Change outlined in the Theory of Change, many of whom have projects funded by LankellyChase. Yet, in a similar way to the applications process, the PCN membership currently only includes one user-led organisation, though all members have user-inclusion processes, some more innovative than others. The shared goal is to shine a light on hidden aspects of the experience of people facing severe and multiple disadvantage and find new ways to empower service users.

There is an acceptance the money available at LankellyChase is not enough to change the system on its own but that communication needs to be improved. Therefore, alongside the grants giving element of the organisation, there is a desire to create a space where people can exchange ideas and network. A space where connections made and conversations happen. Open Space events and a one off 'story telling' event have brought PNC members together with invited guests and service users to enable these conversations to happen. At this stage, the learning from these events is not being used in any formal way.

Designed to inform and guide decision making at LankellyChase is their Theory of Change, which will develop and change as the organisation learns more. Funding applicants are encouraged to refer to the Theory of Change to establish if their ideas are suitably aligned with the foundations, and ideas are not progressed if they are not.

METHODOLOGY

We started by conducting desk based research on user led organisations (ULOs) and non-user led organisations with significant user involvement. From a ‘long-list’ of 52 possible organisations, we mutually agreed on a ‘short-list’ of 18 which we felt were evidence of best practice across a wide spectrum of service user needs. In all organisations considered, service user needs were multidimensional. For example, the primary focus of a user group might be to tackle substance misuse, but this need comes with the knock on effects of criminal justice, homelessness, poverty and poor mental and physical health, as identified in the recent LankellyChase report ‘*Hard Edges*’ (2015).

The final selected list of best practice case studies features a high proportion of examples from ULOs. We felt that these were excellent examples of good practice, and have been the most successful and inclusive because they have involved service users in their design and methods supporting the hypothesis that user involvement is most successful when people with lived experience have influence at all levels of an organisations processes.

Organisation name	Type	Primary User Focus	Method of data collection
Spectrum	ULO	Disability	Telephone interview
CanDo Coffee	ULO	Ex-offenders	Telephone interview
Red Rose Recovery	ULO	Substance misuse	Telephone interview
Experts by Experience	ULO	Mental Health	Telephone interview
Turning Point Scotland (TPS)	VCS	Substance misuse	Telephone interview
CCG User Group	User-led project by CCG	Mental Health	Telephone interview
Healthwatch Oxford	Local ‘consumer champion’	NHS users and those using social care services	Telephone interview

Mend the Gap	ULO	Parents who have been separated from children via social services	Telephone interview
Who made your pants?	ULO	Refugee women	Desk based research
Crisis Skylight - Oxford	VCS	Homelessness	Face to Face interview
A national voice	ULO	Care leavers	Desk based research
National survivors users network (NSUN)	ULO	Mental Health	Desk based research
Emergence	ULO	Personality Disorders Service Users	Desk based research
CoolTan Arts	ULO	Various – limited only to those who have experienced mental distress	Desk based research
Canerows (Sound Minds)	User Led Group at Sound Minds	Mental Health in BME groups	Desk based research
Sandwell Visually Impaired	ULO	Blind or partially sighted	Desk based research
Strengthening Families, Strengthening Communities (SFSC)	User Led Group at Race Equality Foundation	Parents from marginalised communities	Desk based research
Social care institute for excellence	Registered charity	Those using social care services	Desk based research

It was interesting that at least three of the above named organisations refused to engage with our researchers. Others gave the distinct impression that they were uncomfortable discussing their organisation with anyone who wasn't interested in accessing support or supporting its work. This suggested from the offset some of the difficulties facing ULOs in terms of trust and the free flow of information. We are grateful to those we did speak to. Their views are presented within the report, sometimes collectively and at other times individually. Two telephone interviews were also conducted with ULOs who have previously been rejected by LankellyChase for funding.

We held one focus group in Birmingham on 14th January to gather service users' views on funding practices, and their experiences of service user involvement. Ten service users attended plus one PA and two Shaping Our Lives support staff plus a transcriber. The focus group was led by Becki Meakin. Direct

quotations from this focus group are woven through each part of this report. We also conducted a telephone interview with an individual who was unable to attend the focus group.

At the consultation phase, we held a workshop with LankellyChase staff to establish their views on what needs changing in the organisation. The feedback from this workshop will be interspersed throughout the report. A further workshop was held with LankellyChase staff to discuss the recommendations once a draft report was written. Again, feedback and further suggestions have been included.

FINDINGS

The findings below are predominant minor themes which emerged from the data, presented under the three major themes that LankellyChase was keen to understand more about:

- *Organisational Change*
- *Funding*
- *Systems Change*

Interim recommendations based on these findings are presented at the end of the each theme, with one extensive recommendation encompassing several of these interim recommendations following this findings section.

ORGANISATIONAL CHANGE

VALUES

A key component of all interviewed organisations was their value set. Words such as ‘authentic’ and ‘empathic’ were commonplace when describing their work practices. Indeed, both User Voice and Shaping Our Lives are committed to a set of values which guide every decision made in terms of projects undertaken and employee wellbeing. This commitment to a value set is something shared with LankellyChase and an aspect that was highlighted in the workshop as being something staff members felt the Foundation could be proud of.

One of the major values discussed was the determination of user led groups to be solution focused and strengths based rather than deficit focused. Almost all referred to a belief that this is what sets user led

groups apart from statutory services and non-user led groups. An example was given by the founder of *Red Rose Recovery*, a ULO in Lancashire, who found it unhelpful that so many commissioners start initial engagement with an immediate enquiry about the past. Similarly, the CEO of *CanDo Coffee*, a social enterprise project which creates employment opportunities for those considered unemployable, refers to the way participation in the project stops its participants from 'dwelling on the past', which is an essential step in the change process.

Values regarding service users' worth were unsurprisingly paramount. Several interviewees discussed their frustration with the way that statutory services are beginning to recognize the good work done by service user groups, but continued to expect these to be either free or low cost services. One interviewee from the Mental Health focused ULO *Experts by Experience* commented on the unacceptable pay disparity between service users and non-service users, with one example given of £180 an hour for lecturers, but just a £5 Tesco voucher for the service user. Repeatedly, interviewees have been faced with commissioners and funders who they feel simply do not understand the user led movement and therefore do not place appropriate value on the service users' contribution and expertise. The way they contribute might not be conventional, but their expertise is undeniable.

"Wheeling out a service user is NOT service user involvement." (Experts by Experience).

A striking comment was made by one interviewee, that in his experience ULOs often under-priced projects as they feel this is the only way they will secure funding for them or because they lack self-confidence. This then leads to greater stresses on capacity and often failure to complete and a self-fulfilling prophesy. *Crisis Skylight Oxford*, who provide services for those experiencing homelessness have demonstrated the worth they place on 'member' (or user) involvement, by allocating a "*pot of money in the budget to fund members' involvement and [it is] part of the salaried roles of various staff to engage with members*".

The importance of service user involvement to organisations was stressed during interviews, along with a general sense that tangible changes were being made on the back of the involvement. Yet, overwhelmingly, despite working together and feeling like an important mechanism for Systems Change, the experience of ULOs was that service users still felt separated in some way from non-service users.

This is undoubtedly a complex issue, where service users strive to be recognised for the value of lived experience, which in turn creates an automatic divide, and perhaps widening the 'them and us' culture.

This experience was illustrated by a conversation with LankellyChase regarding their Open Space events, where they described attendees as being from the following three groups;

- PCN Members
- "Guests" (Statutory sector commissioners)
- People with lived experience

While this certainly helps to ensure that the three groups are properly represented at the event, it also provides an example of a potential 'us and them' situation that some service users will find reinforces their experience. Of course, this is not intentional and everyone does work collaboratively over the course of these events.

Some telephone interviewees and focus group participants described their experiences of involvement being more tokenistic and some individuals even felt disrespected at events. True involvement would place genuine value on the user as an expert and make the effort to ensure they are embedded within organisations as true equals. As stated by a member of staff from Spectrum, a disability focused ULO, it is irrelevant what someone's impairment is, what matters is their skill set.

There was acknowledgement however that equality can involve more practical steps, and can involve making specific effort to accommodate certain service users' needs. Most organisations are now familiar with the need to be compliant with the Disability Discrimination Act (1995). However, for service users with a more socially chaotic history, the provision needed to accommodate them is sometimes less understood. This was outlined as a barrier for a number of ULOs.

Recommendations: Values

- **Agree a set of values as an organisation about what is really meant by Service User Involvement at LankellyChase; for example, the Diabetes UK service user advisory group has clear terms of reference for its involvement and the people who can become part of the group. The tasks they complete include reviewing publicity materials, and advising on the suitability of campaign messages.**
- **Ensure service users are not treated as a separate group or workers, but that they are equal and central to the workings of LankellyChase.**

INCLUSION

There were differing views on whether a user led organisation should be solely run by people with lived experience, or if a mix of experiences was important. One particular organisation felt strongly that it would be prohibitive to include non-service users as they may be more confident and therefore more influential, simply by virtue of their life experiences. The majority however, did feel that there was a need for involving non service-users, to embrace the spirit of collaboration and inclusion which underpins many of the organisations' value sets. Nonetheless, the presence of a service user at all levels of the organisation was an important philosophy of service user groups.

The recruitment of service users was discussed at length. All organisations discussed their extensive recruitment processes, which are more expensive and resource heavy than standard procedures, but ensure that the right staff are appointed and that both the user and the organisation are safeguarded appropriately. For example, those organisations working with those in recovery stated that it is important to ensure service users are personally ready and at the appropriate stage in the recovery process. If not, an opportunity to work or be involved might be detrimental to all.

Investment in a service user friendly recruitment process was deemed essential. A number of factors were highlighted from across all case studies as important in facilitating this:

- Having service users making the decisions about recruitment, for example service users sitting on interview panels and having a voice all the way to the top of the project. Not only does this ensure appropriate recruitment but addresses notion of tokenism by providing real decision making power.
- Don't measure suitability for employment in standard ways (i.e. a degree or work experience) as service users will very often have experienced multiple obstacles to achieving these. Instead value belief systems, transferrable skills and relevant experience. After all, it is possible to teach a willing and able service user appropriate office skills, but it is impossible to teach lived experience a non-service user.
- Finding a balance in terms of the necessary bureaucracy involved in recruitment and getting to know the applicant. Standard recruitment processes may seem familiar to non-service users but

can be off-putting and can “*kill the essence of what we do by conforming to policies and practices*”. Service users should be central to the redesign of these systems.

Turning Point Scotland (TPS), which provides person-centred support to adults who have experienced substance misuse problems, did not start out with such a strong service user presence, but has become more so through a members’ forum. For that reason, it is of particular relevance to this report in terms of an organisation going through substantial change. Gradually via the members’ forum, members are able to have their voice heard in relation to all policy and practice, including the recruitment of staff. Service users are involved in the whole process of recruitment, from discussions around development of new post, involvement in recruitment open evenings, assessment, and at interview. TPS is very open about the shift in its culture, and now consider that service users are now *more involved* in decision making than staff in some instances which has made everyone in the organisation more confident that new services are appropriate.

In a similar way, *Healthwatch Oxford* have a grants programme, the aim of which is to gather evidence on what service users think of certain services provided by the NHS. All proposals are reviewed by a panel made up of two users and two carers, and then disseminated to a wider group of service users. In the distribution of the grant money, users play a core role in designing questions and the scoring process.

In terms of service users’ attendance on the board, again, this led to mixed views as diverse as “*service users should not be board members*” and “*there should be a minimum of 75% service users on the board*”. Whichever the ratio of service users to non-service users LankellyChase opts for, there should be opportunities for service users to communicate directly with the board on important decisions and issues, and a shared value set regarding user involvement.

Recommendations: Inclusion

- **Adopt inclusive recruitment culture throughout the organisation. Recruit service users using a different yardstick to conventional recruitment measures, placing more emphasis on belief systems than qualifications and work experience.**
- **Seek to embrace transferable skills and provide learning support where appropriate.**

- **Involve service users (including grant holders) in decisions about recruitment, from the development of the job description to the eventual appointment.**

FLEXIBILITY IN APPROACH

As identified in the first staff workshop, LankellyChase considered that a more flexible approach was required in their organisation when thinking about its future. Flexibility was also a common topic within interviews and in the focus group, in terms of how best to work with service users.

The CEO from CanDo Coffee discussed how they seek to work with some of the most disadvantaged individuals in the country. With them comes a set of behaviours that many organisations would deem to make them unemployable, such as body language, verbal communication, and their knowledge of work appropriateness. Yet, CanDo Coffee's only requirement for recruitment is "*anyone who thinks they can*". Consequently, a social support structure is essential for these people, especially at entry level, which can mean employing people on the basis of a 1hr assisted working week.

In a similar vein, Experts by Experience stated that they "*Pride ourselves on working with those who no one else will*", but with this comes careful consideration of their needs and how the organisation can support them. Across the board, it was notable that flexibility was an important feature of all the ULOs in this study, which is related to their values in ensuring involvement can happen, regardless of how difficult it is to accommodate. One example given by Red Rose Recovery was that they changed the way services are delivered, ensuring they were 24/7, not 9-5. Further, Healthwatch Oxford commented that they have focused attention on providing 'flexible support', which means "*support when it is needed by the service user, not when timetables and deadlines demand*".

A *reasonable adjustment* may be a useful aid to enable someone to complete a task or do a job on an equal basis as others; it does not provide the inclusive environment and attitudinal acceptance that is needed to fully involve service users. For example, a screen reader software programme may be an appropriate reasonable adjustment for a visually impaired person to access text documents, however, there needs to be greater understanding and cooperation among others working with that person to enable them to have documents in advance and time to listen to them.

Crisis Skylight engages approximately 50 people per annum in various member involvement activities with the aim of improving their service. Members include rough sleepers, sofa surfers, those in temporary and hostel accommodation, as well as those who are more stable but with have experienced homelessness in the last two years. High numbers of these members have mental health issues, are unemployed, drug and alcohol problems, family/relationship problems, which brings many challenges. Service users are given a £6 voucher for the onsite café to participate at an event. *Crisis Skylight* expressed how they have struggled to find a format for members' forum that attracts more than a handful of members, although they have found that providing food helps.

The ability to be flexible to external changes was also evident throughout the research process, such as the removal of funding or gifts in kind. An example is CoolTan Arts, who are a ULO championing wellbeing in vulnerable groups through arts and creativity. For a variety of reasons, they have been forced to relocate on a number of occasions since their inception, making it essential to also change any space dependent activities. They have adapted and grown with the space they had available to them. Many of the organisations demonstrated a resilience to adapt to failures and sudden changes, something that should be recognised when considering proposals.

However, within the focus group, participants discussed ways in which this need for flexibility could be reduced if funders and commissioners would incorporate resources and skills as well as money in their support package. The following exchange illustrates this:

"The funder could provide resources..."

"If a funder can, that is good. We just have to share task across our team."

"What I have heard of is using Time Banks, swapping skills and resources."

"Skill transfers, using currency other than money. Need to make sure it is overseen properly."

One organisation spoken to, NSUN, work with a network of users of mental health services in England. They have developed a framework (entitled the 4PI framework) to help organisations establish more meaningful service user involvement. Essentially, it concentrates on the following areas which map well onto those raised within this theme so far:

- **Principles:** a commitment to shared principles and values.
- **Purpose:** the purpose of user involvement needs to be clear to all
- **Presence:** service user with relevant lived experience should be involved at all levels of a project or organisation.
- **Process:** the process of involvement needs to be carefully planned
- **Impact:** Involvement needs to make a difference to the lives or the experiences of service users and carers.

Recommendations: Flexibility in Approach

- **Accept and embrace the fact that some service users with a history of severe and multiple disadvantage will not 'fit' with a conventional model and accommodations will need to be made.**
- **Provide peer-led support structures for vulnerable service users.**
- **Recognise the resilience of service user groups to bounce back and manage change.**

FUNDING

LANGUAGE

Undoubtedly, one of the biggest barriers to securing funding, or even attempting to access funding, was language. It was clear that the language used in guidance notes and in the questions asked was not a language shared by all service users. A relevant example is the academic tone to LankellyChase's Theory of Change. No service users had been involved in the development of the Theory of Change, yet it was created to be, in part, used by them directly. The barrier can be caused by inexperience or a lack of formal, traditional education and can have the unfortunate consequence of preventing some of the most innovative people from applying. It also makes the task of completing applications seem more complicated than funders might anticipate. This was particularly the case for those new to the arena. For example, Red Rose Recovery discussed that there was never space to detail the impact of the work they undertake on individuals, such as hope and empowerment. As these are not easily demonstrable outcomes, especially without the use of questionnaires and bureaucratic systems (which were seen as

not especially service user friendly), they felt that they have not relayed the point of their service in the way they would like to. One very valid suggestion for countering this came from a focus group participant who suggested that service users might be the key to creating a more easily accessible language:

“If I don’t like a word or term a funder uses I ask service users what they would prefer, and call it that. Can educate funders that way. You will find them using it 6 weeks down the line.” (Focus Group Participant).

In the focus group, much attention was given to the need to have others help with writing a bid, due to issues around language and understanding. However, this practice was not seen as ideal due to its cost and because it runs the risk of losing the essence of the organisation:

“Lots of jargon involved in doing bids. Consultancies charge an awful lot of money to write a bid for you.” (Focus Group Participant).

“Often a service user has good idea on their own, but needs to find someone who shares that idea and can support that.” (Focus Group Participant).

An important point to raise is the potential for ULOs to adapt ideas just to gain funding, or to conceal the truth if they feel this will not be welcomed. Generally, the value set will prevent a scattergun approach to acquiring funding as outlined above, with the term “dirty money” being used on several occasions to refer to funding given for an idea that was adapted just for financial reasons. There was a genuine acceptance that you will not always have a popular idea. The changing Political landscape was discussed, referring to the way in which certain causes fall in and out of favour. This *constantly changing landscape is a problem for building relationships with funders and even knowing where to go for funding.* In relation to causes that have fallen from favour, one interviewee stated: *“What does government think has happened to those people?”*

However, just for survival, some service users did say they were prepared to make changes to initial ideas, as evidenced in the following quote:

“I will use any language that funder wants me to use. I have no ethics (laughs). I will go to get the money I need to deliver services.” (Focus Group Participant).

Approximately half of the interviewees discussed having a lack of confidence and insecurity when first approaching funders. This is only going to be exacerbated by the clash of languages. A particularly poignant phrase came from the focus group on this matter:

“It’s about breaking the glass wall. You can look in, but not join the party.” (Focus Group Participant)”.

However, interviewees and focus group participants discussed the important learning opportunity that can come from a rejected funding application, if the funder is willing to provide it. Currently, LankellyChase provide written feedback to all rejected applications and verbal feedback for those who ask for it. It is worth considering that some applicants may feel intimidated or too nervous to ask for verbal feedback. Additionally, it might be that if written language was a barrier in the application process, it also prevents learning from the rejection letter.

“If only relationship is an application form and a rejection letter that doesn’t help build understanding.”

Importantly, one interviewee did comment that service users can be known to talk in their own language and tend to assume funders/lay people will understand all the issues surrounding their projects. This can lead to limited information being provided in applications. Because they do it every day, some service users find it difficult to see why other people wouldn’t find their work important or the complications associated with it.

Recommendations: Language

- **Commission service users to help adapt the language LankellyChase uses to ensure it is appropriate for their peers and conveys the intended message. This is particularly relevant to the Theory of Change. At *Shaping Our Lives*, the management board review all documents, which is made up of two people with learning difficulties. This helps to ensure that the end product is accessible to a diverse range of people.**

- Offer peer support for bid writing through workshops, and/or real life examples online as provided by the funder, the *Edge Fund* as discussed later in this report.
- Provide fuller, and ideally verbal feedback for any rejected application to aid development of grant writing skills.
- Generate a network of funding providers and understand their remits, to enable effective signposting for service users to help eliminate the need to change ideas in order to fit with funders' ideologies.

RELATIONSHIPS

Building relationships is seen as such a crucial part of the funding process, and an option shared by LankellyChase. This is especially relevant to those who are struggling to make the first step in the funding process. Relationships between funders and applicants can stall however, due to the fact that the power balance can be seen as skewed in favour of the funder.

This relationship was a particular focus of the staff workshop as well as the focus groups. In the workshops, LankellyChase staff expressed a wish to understand better how grantees hoped to communicate, space to explore openly what grantees need in terms of support and mutual learning. In the focus groups, participants were asked to define both relationships with colleagues and then relationships with funders. The contrast in definitions was vast, which does make the improvement of relationships complicated and an area in need of development. The two lists generated in the focus groups are shown in the table below.

<i>Colleagues</i>	<i>Funders</i>
<i>Trust</i>	<i>Anxiety about meeting expectations</i>
<i>Understanding</i>	<i>Pressure, then relief</i>
<i>Empathy, genuine empathy!</i>	<i>Panic</i>
<i>Affection</i>	<i>Tentative trust</i>
<i>Communication</i>	<i>Faith in their understanding of issues organisation faces</i>
<i>Compassion</i>	<i>Responsibility to deliver</i>
<i>Shared goals</i>	

<i>Partnership</i> <i>Sense of being human</i> <i>Willingness to compromise</i> <i>Confidence in each other</i> <i>Awareness</i> <i>Desire to learn more about one another</i> <i>Space, Shared workload</i>	
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The lack of trust in funders and the sense of unjustness of the process was exemplified by one focus group participant who was certainly not alone in his views:

“[It] takes so long to apply to bids against tight funding deadlines. Put own idea into action, lasts a short time, have to do all the evaluation, all takes time and then funding disappears. The idea works but time spent is so considerable funding doesn’t cover it. Then cannot continue with idea has duplicate funding not available.” (Focus Group Participant).

Having people with lived experience embedded within the funding organisation can help bridge the gap between service users and funders. TPS, HealthWatch and the regional CCG have all found that working so closely with service users has meant for the first time that those who have historically made the decisions come face to face with those who are living with these decisions (both good and bad).

Recommendations: Relationships

- **Again, embedding service users within the organisation to bridge the gap.**
- **For many, the first point of contact should not be on paper. It is important to get closer to the people, understand their skills and what drives them.**
- **Build relationships through increased face to face interaction.**
- **Facilitate ‘funder days’, where service users with ideas can visit a number of funders in one place and open dialogue with more than one organisation. The concept of ‘speed dating’ could be implemented into these days, whereby funders and applicants have the opportunity to meet a large number of new people in a reasonably short amount of time to discuss whether ideas match the ideologies of funding organisations.**

SYSTEMS CHANGE

All organisations spoken to were making a contribution to changing the system, and with some success. For example, *Mend the Gap* have been successful in developing a new system of foster care, through collaborative working between young people with experience of foster care, foster carers and social services. *Who Made Your Pants* is a revolutionary ULO created by a woman who was having “not such a brilliant time”, bringing together refugee women who are utilizing their skills, gaining training and having the opportunity to live a little. *Emergence* are a ULO working to improve service user experience by developing the capabilities, skills and knowledge of the multi-agency workforces, primarily in health, social care and criminal justice, who are dealing with people with a diagnosis of personality disorder.

Yet, when speaking to organisations, it appeared that many were unclear about what “Systems Change” meant and whether they were a part of this. It is unclear the impact this has on organisations looking for funding.

- **Another language blockage, perhaps.**
- **Another insecurity blockage, perhaps.**

GRASS ROOTS & CORE COSTS

There was a huge amount of discourse regarding the need for funders to be less risk averse and fund ideas in their infancy, rather than opting for more established organisations with some track record. This is a concern echoed by almost all participants and ULOs in our study: *“To get funding you need a track record, but to get a track record you need funding”*.

There are a small number of organisations who specialise in taking risks. These were unknown by virtually all interviewees. One such organisation is the *Edge Fund*, who elects a group of service users based on their background and relevant experience, to voluntarily take part in funding decisions. There are around 125 members who make up this group. In December 2014, 34 grants of up to £5000 were given to grassroots organisations looking to make real systems change, unconfined by contractual

obligations. As stated, the decisions on who acquired these grants were made by service users, which makes the organisation unique. In a similar way to LankellyChase, their application process contains five questions and the availability of support to write this is clearly stated. A lot like the ULOs we have reviewed supporting the hard to reach, the Edge Fund try to support ideas and activities that have minimal support elsewhere.

One focus group participant brought together the previous themes of (breaking down) relationships, (having open and accessible) language and (fostering) grassroots, by stating:

“Funders need you and your ideas, they need you to make things happen. They are only money”. This is why I like the idea of dialogue, feedback ‘this is what I am thinking of doing, what do you reckon?’ Funder can appreciate where skill gaps are and they can support. This is an ideal scenario.” (Focus Group Participant).

Furthermore, another focus group participant discusses an alternative in terms of one of the first successes he had with securing funding, which again brings together the preceding themes:

“They were looking for grass roots, funders took them through it step by step, on understanding money would be there, and funders would do all the evaluation work. Removed all the barriers that people found e.g. paperwork. Engaged a lot of people, supposedly hard to reach. Advertised in paper and taken through process step by step but people employed to do all the donkey work. Ideas [were] put into practice as soon as people were getting them without waiting for funding. Did it this way based on what hadn’t worked before.” (Focus Group Participant).

In addition to discussion around grassroots funding, the lack of funding for core costs was given as a very real problem for ULOs. Without this security, organisations are not able to give full attention to the funded project. They may experience anxiety and projects can therefore become vulnerable at the end of the funding period. Through the funding of core costs, it is thought that organisations can give more attention to the work, which may facilitate actual systems change.

LankellyChase's Chief Executive Julian Corner recently stated that *"wherever we find the germs of change, we have to give them all the help we possibly can to become contagious"*. The research up to this point suggests that these germs of change certainly include grassroots organisations as well as organisations struggling to remain sustainable due to ongoing core costs.

Recommendations: Grassroots

- **Not everything funded needs to demonstrate a very obvious systems change, but can start much smaller.**
- **Consider the funding of core costs to enable organisations to dedicate time to innovation and project work, rather than looking for this money elsewhere.**
- **Reserve an agreed proportion of LankellyChase's annual grant allowance for a 'seed pot' to enable those with emerging ideas to climb the first rung of the ladder.**
- **Allow the seed pot to be managed by service users, either paid or unpaid.**
- **Utilise an independent Infrastructure Organisation to hone and develop grassroots ideas of service users to prepare them for larger funding opportunities. The Edge Fund provides a model of user-controlled grass roots funding that allows investment at a lower level in radical and innovative ideas. Although this type of model will inevitably have some failures along with successes, it offers a template for a similar LankellyChase seed fund.**
- **Host open days where grassroots organisations can learn more about LankellyChase Foundation and discuss ideas openly.**
- **Involve service users in the design of research and project briefs, a model widely used by the Joseph Rowntree Foundation in the 1990s.**

EMPOWERMENT

There is a recognition by central government and beyond, that certain groups are underrepresented in the most senior positions, such as women and those from BME communities. Therefore specific schemes are put in place for members of these groups in order to ensure they gain the skills and experience needed to flourish. As described by the CEO of CanDo Coffee, if skills can be acquired and fostered, then a whole family can be lifted out of poverty and the knock on effects that poverty brings. One very important element of Systems Change is enablement through capacity building. There is nothing systemic at the moment that would provide positive discrimination to those with lived experience of severe and multiple disadvantage, to enable them to acquire executive or board positions. If there was, the playing field would become more equal and the system would really be able to change.

Many of the organisations in our research actively aim to enhance both self-belief and capacity in their service user groups and in doing so are leaving a legacy where service users feel more ready and able to change the system. Examples include:

- *SFSC* are a parenting group run by other parents who have experienced similar difficulties in life. Via peer led training, they are able to gain confidence, practical skills and an understanding of certain parenting decisions. This has clear knock on effects for the future in terms of healthy children and the prevention of negative outcomes such as criminality.
- *CoolTan Arts* recruits future trainers from those who have undertaken its training and courses, to maintain the cycle of the user led movement as well as empowering those individuals for a different kind of life.

It was evident that user involvement had captured the imagination of service users within the organisations we focused on. Having the opportunity to contribute and have their voices heard was changing the way that these individuals saw themselves, which has an impact on how others also view them. In one powerful statement, Experts by Experience summarise this in the words of a service user:

“What was once my greatest shame is now my greatest asset.” (Experts by Experience).

Recommendations: Empowerment

- **Recruit on experience and then train what can be trained, such as specific employability skills.**
- **Develop transferable skills e.g. service users are very good at managing their own care/lives but don't know how to apply these skills to project management.**
- **Prioritise applications where ideas incorporate capacity building, or have the scope to.**
- **Build the skills of not only the applicants who are successful (via existing LankellyChase training), but those looking to secure grants but do not yet possess the necessary skills.**

The following is one possible example of how a number of these recommendations could come together in an innovative way to attract more service users to LankellyChase for funding, will help capacity build, and ultimately create Systems Change.

The LankellyChase Challenge

Through in-house social research or Open Space events with PCN members and service users, LankellyChase can identify pressing areas of need relating to Severe and Multiple Disadvantage.

Through national and local press, through the PCN and along with less conventional routes such as through probation offices, service users could be invited to put forward ideas in response to this particular social issue.

A roadshow or workshop would act as a form of distillation whereby a large number of attendees can be worked with to develop ideas, but a much smaller number could be identified as ready to fund. An experienced service user group (an existing group or volunteers) would be best placed to identify those who have not only an innovative project idea, but also the personal skills and the passion to bring the idea to fruition.

Those considered not yet ready for funding will have gained knowledge, confidence and skills from the workshop and may go on to other funders or to develop their idea further through other means, but those identified as ready for funding, they would then work with LankellyChase to develop their ideas.

APPENDIX A

ORGANISATIONAL CHANGE

- Agree a set of values as an organisation about what is really meant by Service User Involvement at LankellyChase.
- Ensure service users are not treated as a separate group or workers, but that they are equal and central to the workings of LankellyChase.
- Adopt an inclusive recruitment culture throughout the organisation. Recruit service users using a different yardstick to conventional recruitment measures, placing more emphasis on belief systems than qualifications and work experience.
- Seek to embrace transferable skills and provide learning support where appropriate.
- Involve service users (including grant holders) in decisions about recruitment, from the development of the job description to the eventual appointment.
- Accept and embrace the fact that some service users with a history of severe and multiple disadvantage will not 'fit' with a conventional model and accommodations will need to be made.
- Provide peer-led support structures for vulnerable service users.
- Recognise the resilience of service user groups to bounce back and manage change.

FUNDING

- Commission service users to help adapt the language LankellyChase uses to ensure it is appropriate for their peers and conveys the intended message. This is particularly relevant to the Theory of Change. At *Shaping Our Lives*, the management board review all documents, is made up of two people with learning difficulties. This helps to ensure that the end product is accessible to a diverse range of people.
- Offer peer support for bid writing through workshops, and/or real life examples online as provided by the funder, the *Edge Fund* as discussed later in this report.
- Provide fuller, and ideally verbal feedback for any rejected application to aid development of grant writing skills.
- Generate a network of funding providers and understand their remits, to enable effective signposting for service users to help eliminate the need to change ideas in order to fit with

funders' ideologies.

- For many, the first point of contact should not be on paper. It is important to get closer to the people, understand their skills and what drives them.
- Build relationships through increased face to face interaction.
- Facilitate 'funder days', where service users with ideas can visit a number of funders in one place and open dialogue with more than one organisation. The concept of 'speed dating' could be implemented into these days, whereby funders and applicants have the opportunity to meet a large number of new people in a reasonably short amount of time to discuss whether ideas match the ideologies of funding organisations.

SYSTEMS CHANGE

- Not everything funded needs to demonstrate a very obvious systems change, but can start much smaller.
- Consider the funding of core costs to enable organisations to dedicate time to innovation and project work, rather than looking for this money elsewhere.
- Reserve an agreed proportion of LankellyChase's annual grant allowance for a 'seed pot' to enable those with emerging ideas to climb the first rung of the ladder.
- Allow the seed pot to be managed by service users, either paid or unpaid.
- Utilise an independent infrastructure organisation to hone and develop grassroots ideas of service users to prepare them for larger funding opportunities. The Edge Fund provides a model of user-controlled grass roots funding that allows investment at a lower level in radical and innovative ideas. Although this type of model will inevitably have some failures along with successes, it offers a template for a similar LankellyChase seed fund.
- Host open days where grassroots organisations can learn more about LankellyChase Foundation and discuss ideas openly.
- Involve service users in the design of research and project briefs, a model widely used by the Joseph Rowntree Foundation in the 1990s.