



Towards

EQUITY

Kitty Arnold

**This report was commissioned by The National Lottery Community Fund.**

**All statistics cited within this report were checked as accurate on 1<sup>st</sup> October 2020.**

**This report frequently uses the following terms and abbreviations:**

**TNLCF:** The National Lottery Community Fund

**DPO:** Disabled People's Organisation

(I have used the term DPO in this report but acknowledge that some prefer DDPO: Deaf & Disabled People's Organisations in recognition of the D/deaf community that consider deafness as a cultural identity.)

**ULO:** User Led Organisation

**DEI:** Diversity, Equity and Inclusion

**With thanks to the following for their contributions:**

Staff at The National Lottery Community Foundation

Disabled People's Organisations across the UK (though I must acknowledge that I was unable to speak with any DPOs based in Northern Ireland).

Illustrations by disabled artist, Kitty Strand [kittystrand.com](http://kittystrand.com)

Representatives from disability charities

Tania Bronstein, Trust for London

Ciaran Rafferty, City Bridge Trust

Becca Bunce, John Ellerman Foundation

Zara Todd, Inclusion and Equity Consultant

Jean-Andre Prager, Special Adviser to the Prime Minister (Welfare and Disability)

Sarah Baker, Cabinet Office Disability Unit

**Whilst many colleagues from TNLCF and DPOs were happy to be named as contributors and have their comments attributed, some preferred to remain anonymous. In the interest of fairness, I have not individually named any contributors from TNLCF and DPOS - and have made all comments from TNLCF staff and DPOs anonymous.**

**This report was written by James Lee.**



## Introduction

The aim of this report is to explore how The National Lottery Community Fund can better support Disabled People's Organisations.

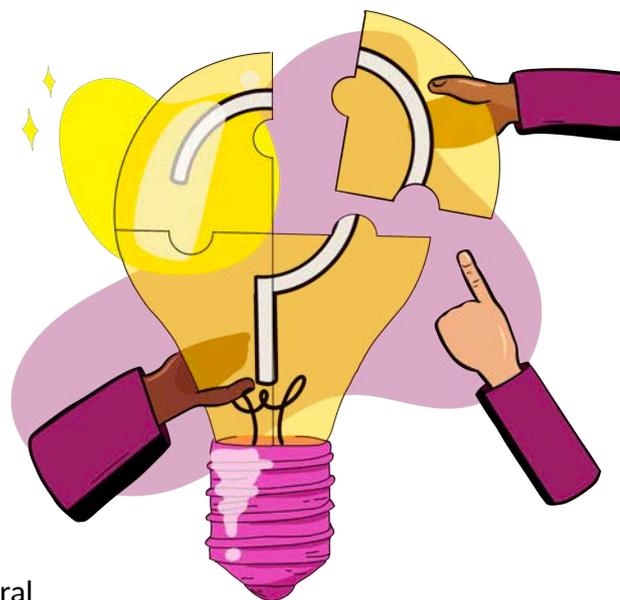
Before we go any further, I should point out that I am (perhaps too literally) adopting NLCF's approach of 'putting people in the lead' by writing this report in (quite a conversational) first-person narrative. They say that 'everyone has at least one good book in them'<sup>1</sup>: turns out mine is a report for TNLCF on funding DPOs.

As I cast around for sensible reasons to forego the tradition of writing reports in the third-person passive voice, it occurs to me that by doing this I am reinforcing several of the key learning points I wish to share.

- As funders, we often talk about 'meeting people where they are' and 'understanding & enabling the authentic voice' of the people we work with. This is my authentic voice.
- When using the words 'disability' and 'disabled people', we should constantly remind ourselves that these are just convenient ways of describing a collective group identity – and that they do not fully reflect the intersectional nature of individuals.
- Whilst I've spoken to a wide range of individuals and organisations for this report, the information I choose to include will, of course, be informed by my own bias. No singular report, no matter how good at creating an impartial voice, can fully be free of the bias of its authors. So, after reading this, please go and seek out other voices on the subject!

In other words: don't rely on the same people to contribute, but continue to encourage new people to join in, to invite fresh perspectives and keep things focused on them.<sup>2</sup>

This work has been informed by conversations I was fortunate to have with a range of DPOs from all over the UK; large disability charities; government officials; other funders and colleagues within TNLCF. I've also added a fair sprinkling of my own lived experience as a disabled person that has worked in the field of grant funding for several years now.



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<sup>1</sup> I won't hold it against you if you feel like adding '**and that, in most cases, is where it should stay**' after reading this report.

<sup>2</sup> If this sentence seems familiar, that's because I've borrowed it word for word from the excellent 'A Meeting of Minds' report by TNLCF. <https://bit.ly/359vCfW>

You know the line about great power and great responsibility? When it comes to funding for disability-related projects and organisations, TNLCF accounts for more than half<sup>3</sup> of all the grants made in the United Kingdom. It is therefore my hope that this report (and others like it) will encourage colleagues both within TNLCF and across civil society to think more often and with greater emphasis on issues of diversity, equity and inclusion. Which is why I am pleased to tell you that this report is full of questions, challenging thoughts and absolutely no answers.

### **Definitions of Disabled People's Organisations aka More Than a Feeling.**

If the core purpose of this report is to understand how TNLCF can better support Disabled People's Organisations, then it would be sensible to first establish how we define a DPO.

I spoke with a wide range of people with different personal and professional experiences of disability and whilst our conversations went into detail on different aspects of this report, I would always begin by posing the same question: how would you define a Disabled People's Organisation?

I asked this question thirty times and as you might guess, I got thirty slightly different answers.

The most common themes assigned to the identity of DPOs were:

- Seeking to support, empower and advocate for disabled people.
- Disabled people occupy the majority of staff and trustee roles throughout all levels of the organisation.
- Operating from a social model, rather than medical model approach to disability<sup>4</sup>.

Some organisations that identify as DPOs follow historically established frameworks for identifying user-led organisations and place percentages against some of these criteria, for example, Inclusion London use the following:

"Their Management Committee or Board has at least 75% of representation from Deaf and Disabled people and at least 50% of their paid staff team are Deaf or Disabled people with representation at all levels of the organisation."<sup>5</sup>

However, other DPOs and some funders which seek to support DPOs (such as the Disability Rights Fund) apply this criteria with broader and more flexible wording. For example, The Alliance For Inclusive Education (ALLFIE) simply use the following wording:

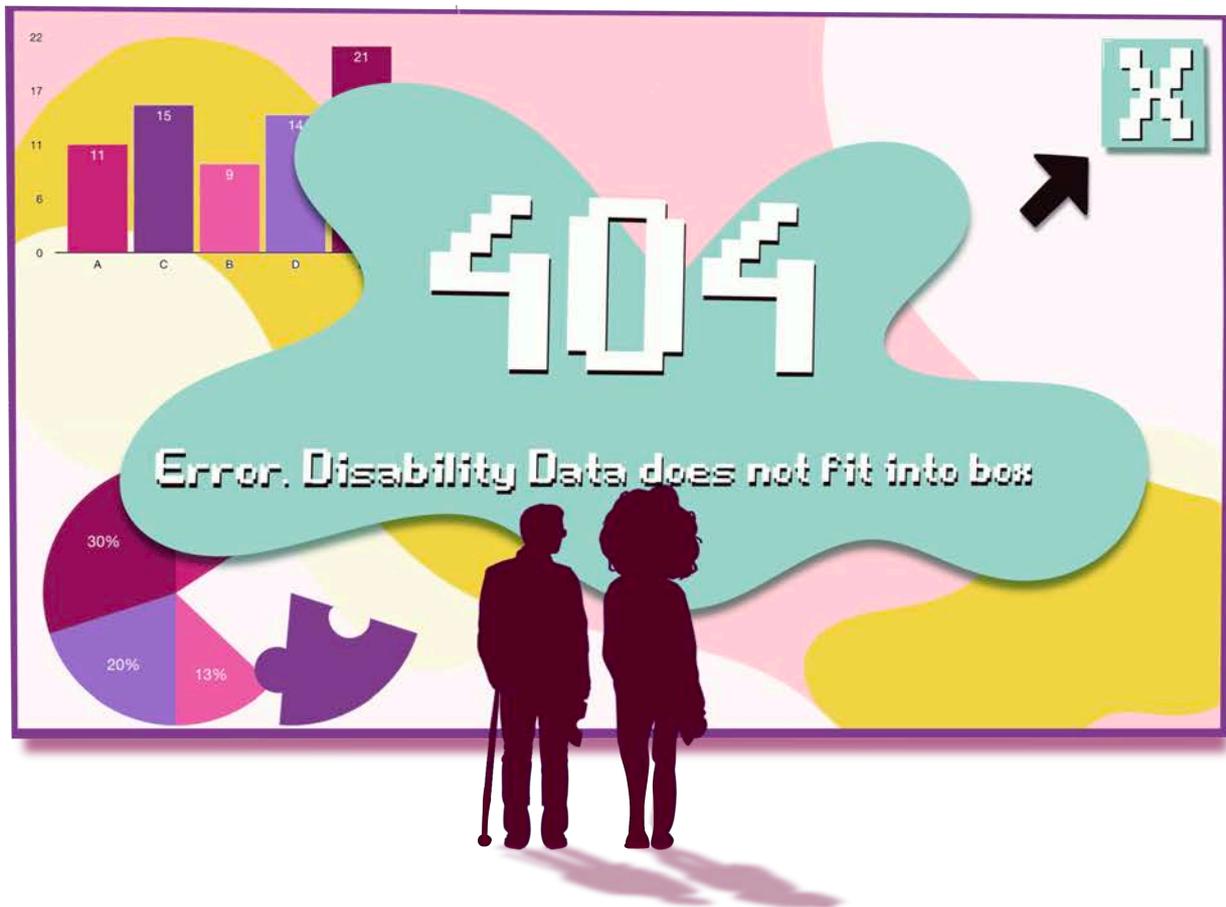
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<sup>3</sup> 14,400 of 24,117 grants tagged with 'disability' as a key word, as tracked by 360 Giving. <https://bit.ly/2EPMU7a>

<sup>4</sup> A definition of the Social Model of Disability & reference to the Medical Model <https://bit.ly/35fuW8E>

<sup>5</sup> Inclusion London: What is a DDPO? <https://bit.ly/3ibnajK>

“A DPO or Disabled People’s Organisation is an organisation which is run and controlled by Disabled people.”<sup>6</sup>



Many funders struggle to identify how much of their funding goes to DPOs and perhaps one of the reasons for this is that whilst there are commonly recognised identifying factors: there is no neat, empirical and universally accepted definition of what a DPO actually is. It’s certainly not something that slots neatly into a database and many people who have tried to quantify what ‘user-led’ looks like will tell you the same.

In 2007, the Department of Health (as it was then known) worked with disabled people to produce 21 design criteria that describe what a user-led organisation (ULO) looks like. The Department of Health also provided these helpful notes of caution regarding the criteria it had developed:

“A ULO does not have to fulfil all of the design criteria and, in reality, most do not.”<sup>7</sup>

“It is broadly recognised that the 21 ULO design criteria are a useful guide to the sorts of characteristics a ULO should exhibit, but they are not considered a prescriptive list.”<sup>8</sup>

<sup>6</sup> ALLFIE: What is a DPO? <https://bit.ly/2FbFpXO>

<sup>7</sup> Department of Health: Understanding ULOs (2007) <https://bit.ly/333Rred>

<sup>8</sup> At this point, anybody reading this report who has a role that involves managing data/quantifying things is welcome to throw their hands in the air and sigh in exasperation.

In this context, it is easy to understand why funders may not be able to identify whether they are funding a DPO/ULO or what the scientific criteria for these organisations would even be.

“One of the key indicators (of a DPO) is the genuine participation and empowerment (of disabled people): it’s important to understand the nuances of what real participation looks like.”

- Tania Bronstein, Trust for London.



Whilst there was some variance amongst DPOs in defining what they are, I think it is fair to say that there was a sense of cohesion in defining what they are not. Whilst DPOs may be registered with the Charity Commission, many people within the disabled community consider the appellation of ‘charity’ to be a disempowering and sometimes insulting term. This ethos is perhaps best characterised by the famous ‘Piss on Pity’ slogan<sup>9</sup> coined by Johnny Crescendo (Alan Holdsworth) during the 1990s in protest of the patronising way that disabled people were (and some argue, still are) exploited by disability charities as objects of pity in order to raise money. Some DPOs describe themselves as service delivery organisations; others prefer to be described as civil rights organisations; almost all reject the notion of being a ‘charity’.

“There are a lot of past practices which are really awful and we have to own that – but the way we work today is very different to twenty, thirty years ago. We actively seek to employ disabled people and people with lived experience, we have disabled people as our trustees, we don’t formulate any strategies or commit to any actions without consulting extensively with disabled people. We know we have inherited a position of power and we want to give that power to disabled people.”

- Anonymous, Disability Charity.

There is, at present, no comprehensive dataset on DPOs across the UK. There is no accurate or up to date list of DPOs that funders, policy-makers or others with an interest in working with/supporting DPOs can use to quickly find these organisations. Attempts to maintain any form of up to date indexes of DPOs are few and far between. The most populated lists tend to be based in quite narrow geographic confines: whilst the Global Disability Watch has an

<sup>9</sup> The Independent: Piss on pity <https://bit.ly/34GfDnA>

international membership list of just 20 DPOs<sup>10</sup> a regional organisation such as Inclusion London has a directory of over 50 DPOs<sup>11</sup>. ULOs and DPOs were already in a precarious position pre-pandemic<sup>12</sup> and this situation has only worsened over the course of 2020. With no resources forthcoming to map the sector and keep the information updated, this situation is unlikely to change.

It is my suggestion that the previously mentioned common themes would serve as a good framework for identifying DPOs but it is important to remember that any framework should be applied with flexibility in mind.

### **Challenges Faced by DPOs and the Support Needed from Funders aka Knockin' on Funders' Doors.**

It is impossible to fully understand the challenges that DPOs face without understanding some of the history behind the Disabled People's Movement in the UK. Don't worry, I'm not about to launch into a history lesson<sup>13</sup>.

In brief, largely due to a history of institutionalisation and lack of access to education, employment and other opportunities: disabled people are often at the very bottom of most measures of socio-economic equality – something which is especially true for disabled people who face intersectional disadvantages.

If you look at the requests TNLCF receives for funding to support disabled people, you begin to get a sense of the breadth of disadvantage that disabled people face. The work that TNLCF supports is aimed at a disabled community that is financially impoverished; often denied access; socially excluded and constantly challenged over the right to an independent

“Disabled people were hit harder than most by austerity. The benefit cuts combined with the narrative of who was deserving or undeserving of support left a constant climate of fear for many. This fear was on top of barriers - discrimination - already faced by disabled people in everyday life. It can break your trust in systems and people. It has caused profound social isolation for many. It makes it harder to communicate and connect socially to those who have not got lived experience of instability.”

- Becca Bunce, John Ellerman Foundation.

life. It is then, perhaps, little surprise that organisations of disabled people can be significantly disadvantaged when compared to their peers.

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<sup>10</sup> Global Disability Watch: Member Organisations <https://bit.ly/34C5loG>

<sup>11</sup> Inclusion London: DDPO Directory <https://bit.ly/3d8dTHG>

<sup>12</sup> Community Care: Accelerating closure of ULOs <https://bit.ly/2HpDAaH>

<sup>13</sup> The Centre for Disability Studies is a good starting point <https://bit.ly/3divNaH>

Before we go further, it is first important to emphasise that all of the ideas I explore in this section should be approached through the lens of equity rather than equality. Why equity rather than equality? In my opinion, one of the best explanations of the difference between the two can be found in this sentence from the Social Change UK website:

“Although both promote fairness, equality achieves this through treating everyone the same regardless of need, while equity achieves this through treating people differently dependent on need.”<sup>14</sup>

“There is a question of whether we are meeting disabled people where they are - or are we just looking for people and organisations that easily ‘fit the mould’ of what we always fund? To create change funders need to get out their comfort zone with what they are funding. We need to feel challenged by the power that groups we fund amass. This is a sign of progress. This is successfully funding social change.”

- Becca Bunce, John Ellerman Foundation.

We must first move towards equity in our funding before we can achieve equality.

There are many ways in which funders such as TNLCF can be better allies and greater sources of support for DPOs. I spoke with thirteen DPOs as part of the research for this report and asked each of them to share the barriers they had encountered when seeking to access funding and support. The answers I received can broadly be summarised by the following diagram.



<sup>14</sup> Social Change UK: Equality and Equity <https://bit.ly/3iGfPln>

I should stress that this is a very simplistic representation of quite a complex issue. It is not my intention to make a judgement on the relative merits of DPOs and non-DPOs. I am not trying to suggest that one type of organisation should be funded over the other: I am just exploring the barriers that DPOs face, as told to me by DPOs.

Many of the DPOs that I spoke to cite a range of factors which contribute to their lack of capacity to apply for funding and support. This included the fact that most had a very small number of full-time staff<sup>15</sup>, which often meant that there was no dedicated role for business development or securing funding to grow the organisation.

It is not unheard of for the person at a DPO who is writing bids for funding to also be the person who will deliver the work for which funding is sought; the finance officer; the office cleaner and the chief executive.

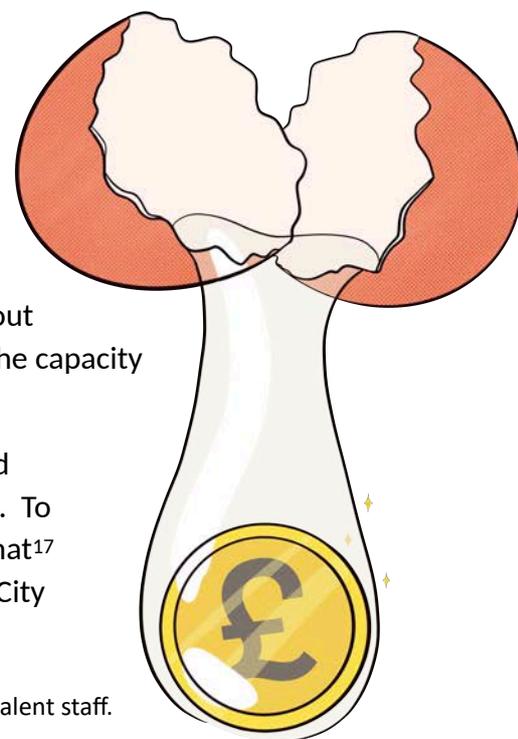
Consequently, many DPOs without this dedicated role spoke of difficulty in knowing how to articulate the value of their work against the criteria for funding that TNLCF and other funders use when assessing an application.

“It takes knowledge and skill to tell the difference between a well-written application that is extractive of a community and one that is co-produced.”

- Zara Todd, Inclusion and Equity Consultant.

There is clearly a specific skillset required to secure funding from trusts and foundations: why else would organisations with the means to do so employ people for this dedicated purpose<sup>16</sup>? Sadly, this is a resource that many DPOs do not have access to and poses a financial chicken and egg conundrum. Which came first: the funds or the fundraiser? This often leaves DPOs locked out of the larger amounts of funding which would help them to add the capacity that they need for sustainable growth.

This is an issue made worse by the lack of accessible guidance and consultation material published by both TNLCF and other funders. To date, I have only found a few pieces of guidance in easy read format<sup>17</sup> published by grant funders in the UK: the funding strategy of the City



<sup>15</sup> Of the 13 that I spoke to, only 2 DPOs employed more than 3 full-time equivalent staff.

<sup>16</sup> Charity Job: Trust Fundraiser jobs <https://bit.ly/2FdlFn0>

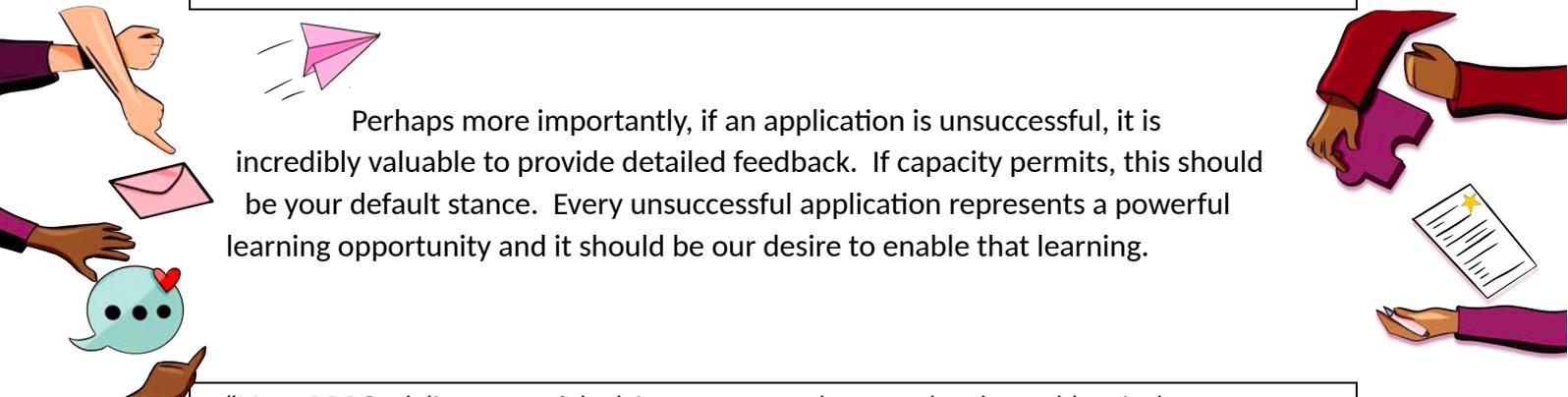
<sup>17</sup> Gov.uk: What is Easy Read? <https://bit.ly/3lSdC59>

Bridge Trust<sup>18</sup> and application guidance from Trust for London<sup>19</sup> and the Arts Council<sup>20</sup>. TNLCF itself provides some easy read guidance for its 'Leaders with Lived Experience Programme' but colleagues within TNLCF noted that the slow development of easy read guidance for other programmes. If you find any other grant funding resources in an easy read format, please let me know!

Whilst having an accessible application process is important, we should also give consideration to what happens after an application has been received. If an application from a DPO is approved, it is important to ask at the outset whether there are any actions you can take as the funder to make your relationship with the grantee more accessible.

"Fundamentally, this work is about relationships – and the most fruitful ones are the ones where you have someone who gets what you do. We are funded by the lottery but feel that the relationship is very procedural and there's little opportunity for us to give back, little opportunity for them to learn from us. The limited engagement we've had has felt a bit like a tick-box exercise."

- Anonymous, DPO.



Perhaps more importantly, if an application is unsuccessful, it is incredibly valuable to provide detailed feedback. If capacity permits, this should be your default stance. Every unsuccessful application represents a powerful learning opportunity and it should be our desire to enable that learning.

"Many DDPOs deliver essential advice, support and casework – the problem is that some funders may see this as 'boring' and we sometimes fail to recognise how transformational the 'boring' work can be. Not many DDPOs engage in the kind of work that would excite funders. Changes in local authority commissioning brought about by a decade of austerity cuts have restricted the areas of work that DDPOs are funded to deliver. As a result, few DDPOs nowadays engage in the kind of work that funders would view as exciting."

- Tania Bronstein, Trust for London.

<sup>18</sup> City Bridge Trust: Bridging Divides <https://bit.ly/3jEojkG>

<sup>19</sup> Trust for London: Funding Guide <https://bit.ly/3dfUHHV>

<sup>20</sup> Arts Council: Project Grants <https://bit.ly/2GHV07k>

Funders often talk of the power imbalance between funder and grantee: in the context of this report I should point out that there also exists a power imbalance between small DPOs and large disability charities.

All of the DPOs that I spoke to were critical of the disability charities whom they depict as being occupants of space and recipients of funding that should go to DPOs.

That said, there was also a recognition of the fact that disability charities currently represent an essential lifeline to many disabled people; have a reach and visibility that DPOs do not; and are able to use their established power and influence to be effective allies.

The desire to serve as allies to DPOs was expressed by all of the disability charities that I spoke to for this report. Alongside this was a recognition from both DPOs and disability charities that you can be a valuable ally for disabled people without needing to have any lived experience of disability.

“I do believe that many disability charities, especially the biggest ones, have a vested interest in keeping disabled people segregated, in keeping us second-class, in keeping us down – because the moment we rise up, they are no longer needed.”

- Anonymous, DPO.

When writing this section of the report, I began to wonder whether the question should not be “how can we better support DPOs” but rather “how can we better support disabled people?”.

I wrestled with this thought for some time because it starts as something of a circular argument about the comparative merits of DPOs and disability charities but soon becomes a tangle of spaghetti. It is certainly a question that prompts many more thoughts that I have struggled with as a disabled person and grant funder.

*What is the most effective way to address the inequality faced by disabled people?*

*With a finite budget, if I actively seek to fund DPOs, what is the consequence for other organisations?*

*What about the fact that many ‘disability charities’ actively seek to employ disabled people at all levels of the organisation, genuinely operate from a social model perspective and deliver very good work in support of disabled people?*

Regardless of where we stand on the comparative values of DPOs and disability charities, there are some good general rules of thumb to follow when seeking to fund work that empowers disabled people.

“One of my great frustrations is that much of the support we see on offer for disabled people aims to ‘fix’ disabled people – to somehow make disabled people fit into the existing systems – when really, I think we would see greater value in interventions that ‘fix’ the system.”

- Anonymous, DPO.

Look for the active involvement of disabled people in the planning of an application. Ask whether disabled people have a voice in the delivery of work. Think about the type of relationship the applicant has with disabled people and how this is reflected in the outcomes they seek to achieve.

### **Working With Our Colleagues aka You Oughta Know**

In addition to speaking with DPOs and other external stakeholders, it is important to also consider the views of internal stakeholders at TNLCF.

I was struck by the number of colleagues within TNLCF who claimed to have little to no knowledge of disability then went on to demonstrate a strong awareness of the issue over the course of our conversation. What I take from this is the need to encourage colleagues to feel empowered and have a voice on issues they may not consider themselves to own.

Equally, colleagues who are seen as ‘owning’ or being an ‘authority’ on disability should not be defined by this knowledge alone.

“I’m happy to use my lived experience and I’m happy to be consulted (about applications) by colleagues who recognise my lived experience but I do struggle with the weight of expectation and the feeling of imposter syndrome when I’m asked about experiences of disability that I do not have.”

- Anonymous, TNLCF.

“Funders will make better decisions (on applications about disability) if they support their staff to own their lived experience and use it to inform their work.”

- Zara Todd, Inclusion and Equity Consultant.

There should be a recognition that any lived experience of disability does not automatically qualify you as an expert on the experience of any other disabled person: to do so places an unfair burden of assumed knowledge on an individual.

It was acknowledged that the way in which TNLCF captures data and identifies projects as having a focus on disability could be improved. At present, applications for funding can self-declare the types of communities they will work with and support. Some applications may state an intention to work with multiple ‘types’ of disadvantaged communities but whether they actually do so and to what extent can be difficult to verify due to the sheer volume of work that TNLCF supports.

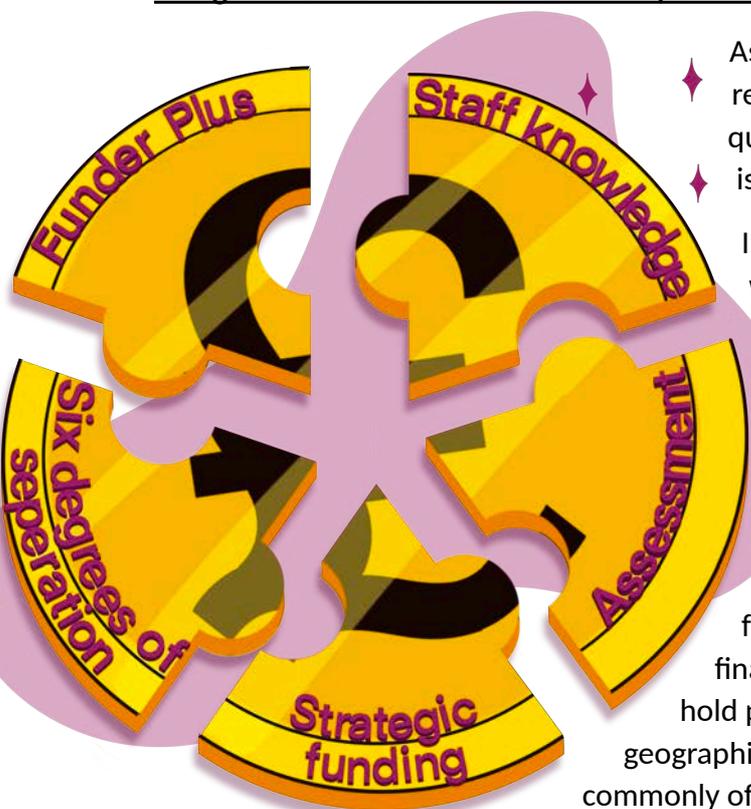
“I’ve often thought that I would have loved to spend more time following up with this organisation or that project because we fund some really amazing work – but it’s difficult to find the time to do this with my constant pipeline of work.”

- Anonymous, TNLCF.

This means that, in theory, a youthwork project might state that they will work with people experiencing a wide range of disadvantages including disabled people, they could deliver an open-access programme that is willing to support any disabled people who seek to access it - but even if no disabled people actually access the service, it is still considered to have been funding that went towards a disability-related project.

Whilst I have no doubt that 'disability' represents a significant part of TNLCF's funding portfolio, I do suspect that the true scale of support received by disabled people thanks to funding from TNLCF may be somewhat inaccurate.

### Things We Can Do aka Sweet Dreams (Are Made Of This)



♦ As I mentioned in the introduction to this report: I am mainly here to prompt further questions rather than provide answers to the issue of supporting DPOs.

I do, however, have five suggestions for action which I would encourage colleagues at TNLCF and other funders to build upon if we wish to better support DPOs.

- Developing the 'Funder Plus' offer.

'Funder Plus' is an increasingly commonly used phrase that refers to the support funders can offer to civil society beyond the financial means at our disposal. Many funders hold positions of privilege and power in both a geographic and thematic sense. Examples of things commonly offered as part of a funder plus approach

include the use of places and spaces to host community events and meetings; paying for environmental and accessibility audits to help organisations be more sustainable and inclusive; sharing relationships with partners from other sectors and actively advocating for the work that we support.

"It's good to offer support but you have to be careful not to do so in an overwhelming way – I've had some organisations come back and say to me that they have too many offers of support – they cannot cope or keep up with everything on offer!"

- Tania Bronstein, Trust for London.

If you map the assets that your organisation has at its disposal, what else can you offer a grantee beyond a grant itself? What impact would this have? DPOs have specifically mentioned the value of space for events, funders sharing their work (e.g.: through our own channels) and of connections to other organisations in their area.

“The opportunity to connect with other DPOs is always welcome but we don’t necessarily just want to be connected within the disability space – some of our most effective campaigning work has come from alliances with other organisations outside of disability, where we have challenged issues on an intersectional basis.”

- Anonymous, DPO.

- Staff with knowledge and confidence in disability.

Grant funders that have a familiarity with the subject and the confidence to talk about disability with colleagues and grantees are an essential part of providing better support to DPOs. I certainly believe there is value in providing disability equality training within your organisation.

What else might we do to build this knowledge and confidence? Are there models we can emulate that are based on providing placements/secondments or other ways of sharing and gaining experience?

- Changing how and what we assess.

If we wish to better support DPOs then it would seem sensible to have (at least internally) an agreed criteria and way of collecting information on an organisation that lets us identify them as a DPO. Following the earlier point in this report on equity and equality, it is also worth thinking about our criteria for ‘good’ and our reasons for wanting to explicitly support DPOs in the first place.

“I can see the logic of only funding DPOs but this fails to acknowledge people’s entry point to the space (of disability). If you are the parent of a disabled child or if you are newly disabled, the odds of you finding a DPO are really quite slim. Potentially a good halfway house would be to encourage more partnership working between DPOs and disability charities.”

- Anonymous.

Consider the formats and language that we use – are we communicating in an

accessible way? Is there any targeted support that we can offer to make it easier for DPOs to engage with us?

- Strategic funding initiatives and different types of support.

It is right that TNLCF seeks to serve a broad range of communities given the source of its funding. However, if we commit to taking an equitable approach to funding DPOs and creating positive changes to the lives of disabled people then there is a strong argument for the provision of a strategic fund targeted specifically at DPOs.

“You’ve got to realise that we don’t have the same infrastructure, the same resources to compete with these big organisations – and every pound you give them is just entrenching that situation.”

- Anonymous, DPO.

“The problem is that we’re all competing for funding and this creates a capitalist market in a sector where that’s not supposed to exist – but it does – and the commodity is the social value of our work.”

- Anonymous, Disability Charity.

If you were to provide funding specifically for DPOs, what would the criteria be for that fund and who should set those criteria? What other targeted interventions could be of value to build the capacity of a DPO?

- Six degrees of separation.

Perhaps foremost amongst all funders, TNLCF is well positioned to offer some of the most meaningful opportunities to platform good ideas and innovation. TNLCF enjoys a strong relationship with the government, is a key stakeholder across many communities at a local level and has significant public recognition. It would be hugely beneficial for DPOs if TNLCF could help them connect with other organisations in their space – both geographically and thematically.

What is the role you can play in making these connections – is it a simple introduction or a longer role of facilitation? How can you capture the impact and any benefits of having made the connection?

Individually, each action may only yield incremental improvements but put together collectively – and if actioned by more funders beyond TNLCF – they can have a long-lasting and significant impact.

The final thought I will leave you with is this: as funders, we have a responsibility to continually move towards equitable access to our support for all of the communities that we seek to serve.

It is important to see this report as just another step on that journey.

