

**Inclusion  
London**

Supporting London's Deaf and  
Disabled People's Organisations



The National Lottery Community Fund



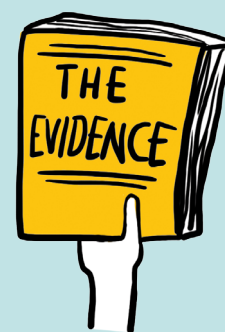
**25 YEARS OF THE  
NATIONAL LOTTERY**



Most of the illustrations in this document have been drawn by

*Sandra Howgate*

## Contents



|   |    |
|---|----|
| Introduction  | 4  |
| Methodology   | 5  |
| <b>Section 1: Overview of findings: What does the DPO sector look like in 2021?</b> |    |
| Definition of a DPO   | 6  |
| Overview of key findings  | 6  |
| <b>Section 2: Research Findings:</b>  |    |
| What Disabled People's Organisations do and contribute                              | 14 |
| DPOs operating in England: coverage and gaps  | 16 |
| Intersectional Issues   | 19 |
| Funding Issues  | 22 |
| Fragmentation and Isolation of the DPOs   | 34 |
| Marginalization from Decision Making  | 38 |
| Relationships with Local Authorities  | 39 |
| Internal Issues   | 41 |
| Little Capacity to Support Current and Future Leaders                               | 42 |
| Limited Capacity to Reach out to Younger Disabled People                            | 46 |
| Covid-19 Disabled People and DPOs   | 49 |
| <b>Section 3: Meeting the needs of our DPO sector</b>                               |    |
| Overview: A new vision for DPOs   | 52 |
| What infrastructure support does the DPO sector need?                               | 54 |
| What movement building support does the DPO sector need?                            | 56 |
| What voice & policy support does the DPO sector need?                               | 58 |
| What could regional and national infrastructure look like?                          | 60 |
| List of Contributors  | 64 |

# Introduction

This report has been produced from the research carried out by 8 Disabled People's Organisations funded by the National Lottery Community Fund (NLCF) to understand the current challenges and needs of disability equality organisations run by and for Disabled people<sup>1</sup> working in England.

Despite Disabled People's Organisation (DPOs) proud and proven track record in creating social change and providing empowering peer support services to Disabled people, DPOs across England are in an increasingly precarious situation. Many DPOs have closed or lost funding and many are reporting increasing marginalisation from funders and decision makers – all at same time as demand and need for DPOs is increasing amongst Disabled people hit by a combination of structural inequality, rising poverty and Covid-19.

This is not an entirely new experience. The challenges of the DPO sector across England have been previously documented<sup>2</sup>. However, this situation has significantly deteriorated over the past decade.

Things are getting worse not better for the majority of Disabled people with rising rates of poverty, exclusion, poorer life outcomes and increasing hostility all well documented<sup>3</sup>. This is also the case for DPOs. The financial crash, followed by a decade of austerity have resulted in many of the gains won by the Disabled people's movement and DPOs in the 1980's to mid-2000's being eroded.

This report gives a snapshot of the state of the DPO sector in England in 2020-2021 and puts forward a set of recommendations that if implemented would transform DPOs ability to tackle the deepening structural inequalities faced by Disabled people in a post covid world<sup>4</sup>.

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<sup>1</sup> We use the term 'Disabled people' in this report to cover the following groups of people: people with physical impairment, visual impairment, hearing impairment, people with long term health conditions, people with hidden impairment, Deaf people, people with learning difficulties, people who experience mental distress and people who are neuro-divergent

<sup>2</sup> Mapping the Potential for User-Led Organisation's in England" report Maynard-Campbell et al, 2007 and Thriving or Surviving: Challenges and Opportunities for Disabled People's Organisations in the 21st Century" Bashall et al, 2008

<sup>3</sup> See: (2018). Is Britain Fairer? The state of equality and human rights in Britain. [online]. Available at: <https://www.equalityhumanrights.com/sites/default/files/is-britain-fairer-accessible.pdf> .

See: <https://www.equalityhumanrights.com/en/publication-download/cumulative-impact-living-standards-public-spending-changes>. And <https://data.london.gov.uk/dataset/welfare-reform-2019> .

See : [https://socialmetricscommission.org.uk/wp-content/uploads/2019/07/SMC\\_measuring-poverty-201908\\_full-report.pdf](https://socialmetricscommission.org.uk/wp-content/uploads/2019/07/SMC_measuring-poverty-201908_full-report.pdf) ) .

See <https://www.trustforlondon.org.uk/publications/supporting-disabled-people-into-work/>

Rieser, R. (2018). Where are we now with Inclusive Education? <https://www.allfie.org.uk/news/blog/now-inclusive-education/>

See (Smith, N.A. and Phillips, D. (2019). English council funding: what's happened and what's next? Institute for Fiscal Studies briefing note. [online] 29 May. Available at: <https://www.ifs.org.uk/publications/14133>). And <https://www.ippr.org/research/publications/social-care-free-at-the-point-of-need>

<sup>4</sup> 6 out of 10 covid deaths are Disabled people: (C. Putz and D. Ainslie, 2020), 'Coronavirus (COVID-19) related deaths by disability status, England and Wales: 2 March to 14 July 2020'. Available at: Coronavirus (COVID-19) related deaths by disability status, England and Wales - Office for National Statistics ([ons.gov.uk](https://ons.gov.uk))



## Methodology

This research has been carried out by 8 Regional DPOs under the co-ordination of Inclusion London<sup>5</sup> and Reclaiming Our Futures Alliance (ROFA)<sup>6</sup> – a grassroots network of DPOs in England. To gain the most accurate picture of the DPO sector across England we identified DPO partners who had the capacity and reach with local DPOs to carry out the data collection in their region. A secondary aim was to build the capacity of DPOs regionally through the research, so each partner received funding to support their involvement.



The 8 regional research partners were:

- **North Yorkshire and the North East** - Equality Together, Bradford
- **South Yorkshire and Humberside** - Disability Sheffield
- **The North West** - Greater Manchester Coalition of Disabled People (GMCDP)
- **The Midlands** - Birmingham Disability Resource Centre
- **East Anglia** - Equal Lives
- **South East** - Spectrum CIL
- **London** – Inclusion London
- **The West** - West of England Centre for Inclusive Living (WECIL)

There were 4 main methods of data collection and research:

- A mapping exercise to identify the DPOs operating in each region
- An e-survey completed by 104 DPOs across England
- 24 focus groups, involving 70 plus Disabled people from local pan-impairment DPOs, single impairment DPOs, intersectional DPOs and single issue DPOs

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<sup>5</sup> [www.inclusionlondon.org.uk](http://www.inclusionlondon.org.uk)

<sup>6</sup> <https://www.rofa.org.uk/>

# Section 1 - Overview of findings:

## What does the DPO sector look like in 2021?

### Definition of a DPO

DPOs take many forms but the defining characteristics are that they are run and controlled by Disabled people and have an implicit or explicit commitment to the social model of disability<sup>7</sup> and promoting/advancing the human rights of Disabled people.

For the purposes of this research the following definition of a DPO was adopted:

A DPO is an organisation whose constitution requires it to have a membership and board with a majority of Disabled people<sup>8</sup> and whose objectives are the rights and equality of Disabled people.

### Overview of key findings

#### Number of DPOs and geographical coverage in England

From our DPO mapping exercise we identified 395 DPOs operating across England that met this criterion. Here is a breakdown by region:

| Region                         | Number of DPOs |
|--------------------------------|----------------|
| East                           | 31             |
| North West                     | 71             |
| North East                     | 44             |
| South Yorkshire and Humberside | 18             |
| Midlands                       | 26             |
| South West                     | 55             |
| London                         | 123            |
| South East                     | 27             |
| <b>Total</b>                   | <b>395</b>     |

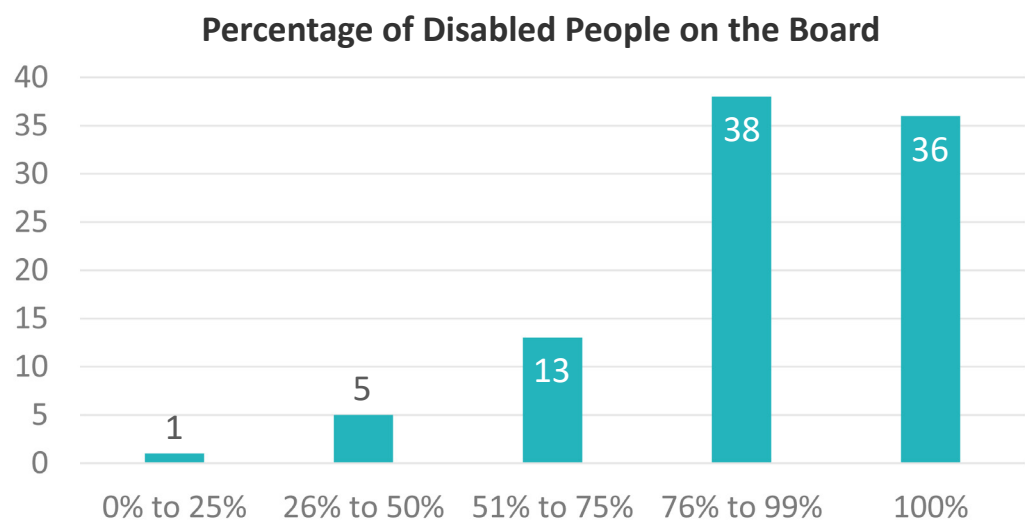
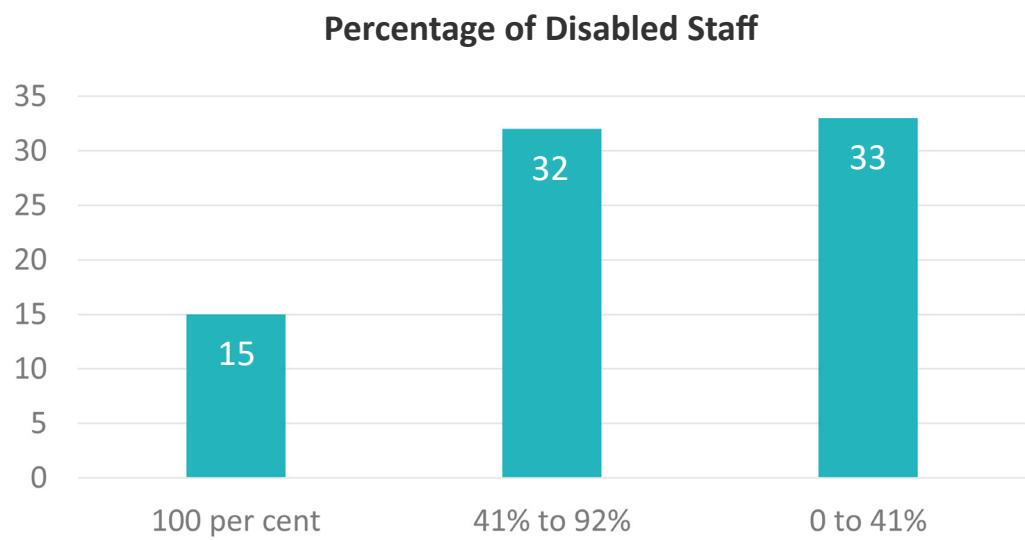
<sup>7</sup> See <https://www.inclusionlondon.org.uk/disability-in-london/social-model/the-social-model-of-disability-and-the-cultural-model-of-deafness/>

<sup>8</sup> Many DPOs use a stricter criteria requiring Disabled people to make up 75% of Board and over 50% of paid staff representation but it was decided to operate the simple majority criteria for this research in order to include the maximum representation and involvement of DPOs in the research.

Some of the key features that distinguish a DPO from other disability organisations are highlighted in the following tables using the results from the e-survey questionnaire completed by 104 DPOs.

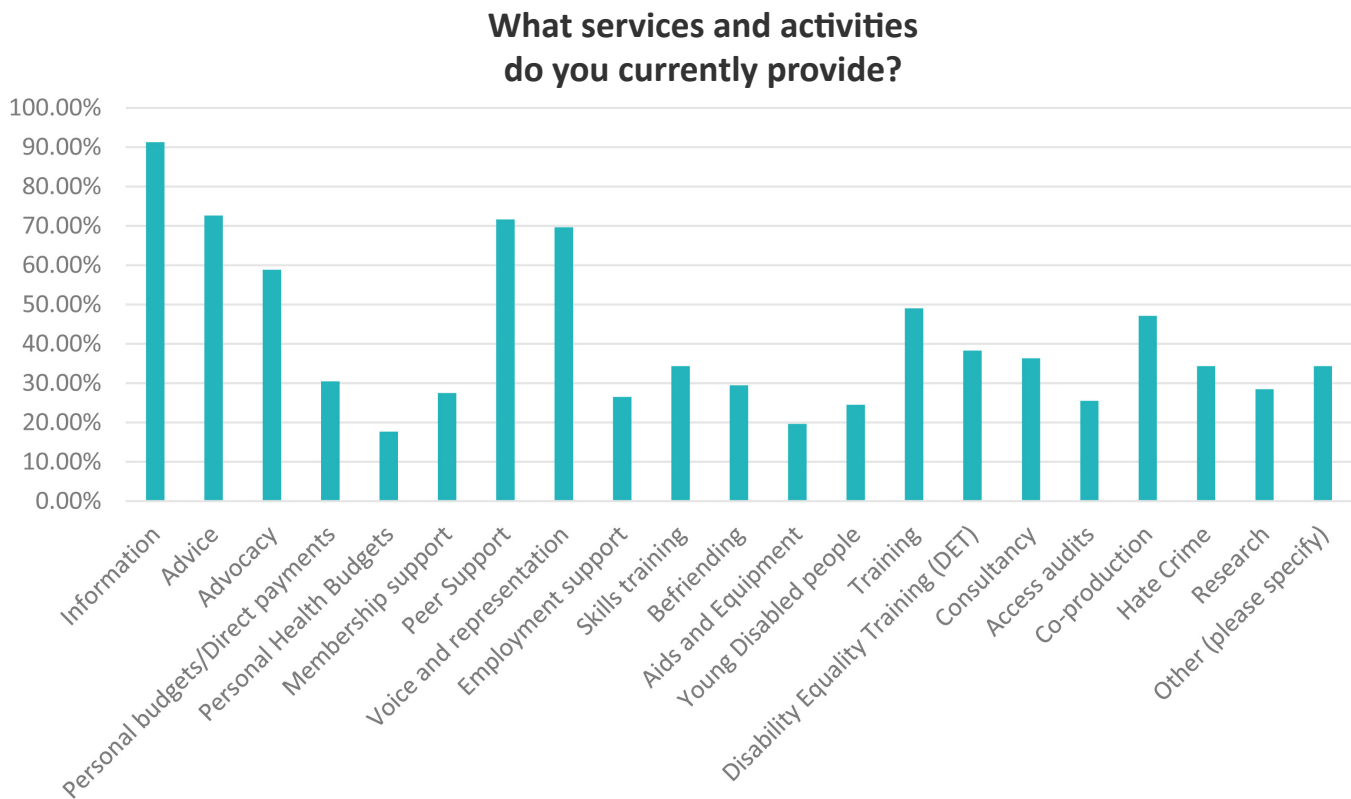
**DPOs are run by and for Disabled people:**

This graph shows how DPO services are peer led, run and delivered by Disabled people for Disabled people at both a staff and Trustee/Board level.



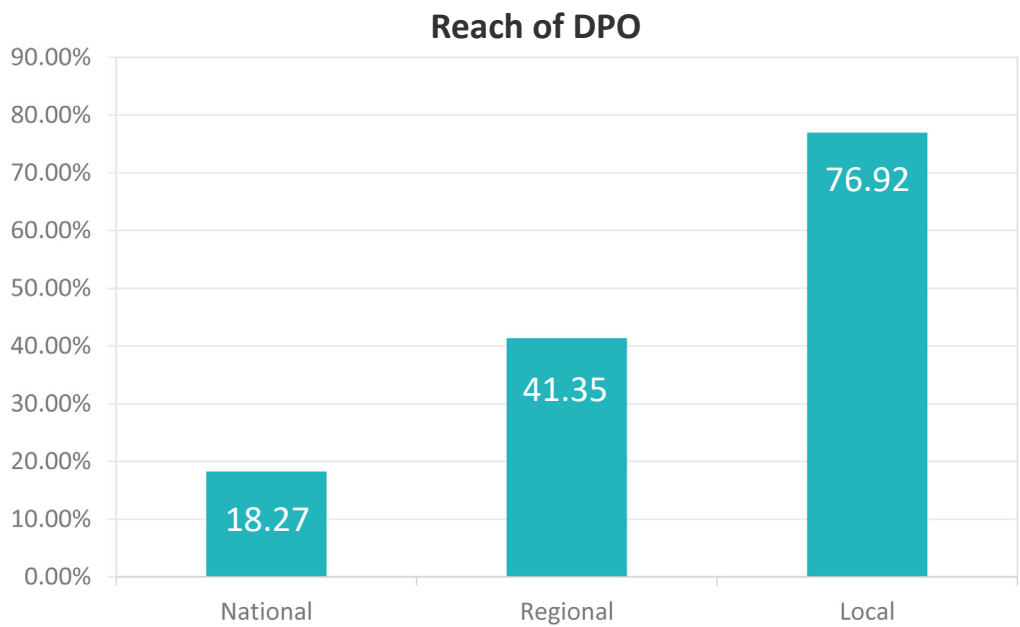
## The range of support DPOs provide:

The graph below illustrates the wide range of peer-led services and activities carried out by DPOs generally on very modest levels of income:



## Reach of DPOs:

The majority of DPOs in our study operate locally but some operate across their regions. Most of the national DPOs are impairment specific, inter-sectional or single issue organisations covering areas such as inclusive education:

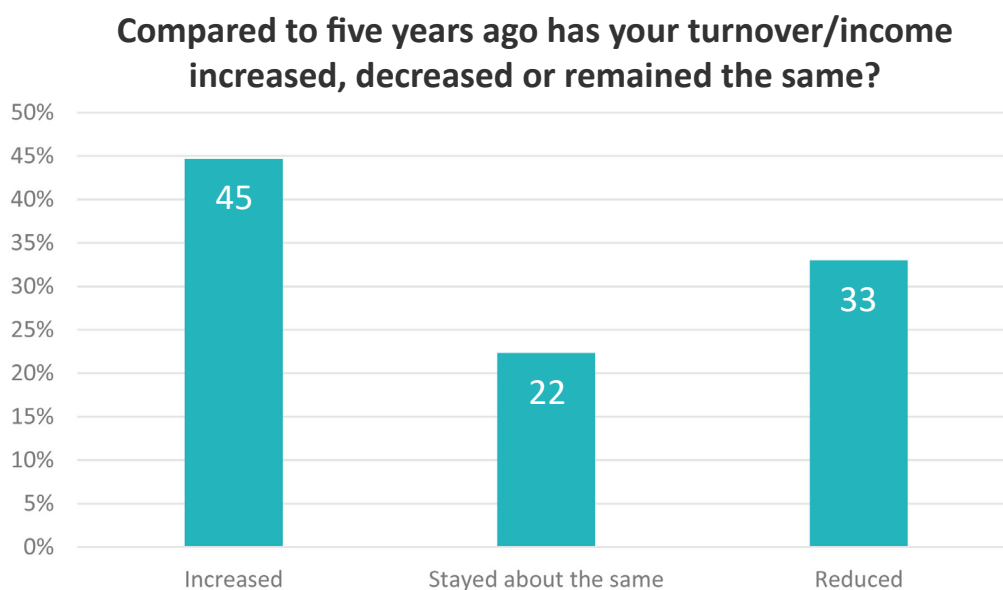


## Reach of DPOs: Income of DPOs:

The graph below shows that the vast majority of DPOs have an income of under £500,000 p.a. with a very significant number operating on incomes of less than £100,000 p.a. Likewise, only a small percentage had incomes of over £500,000 which contrasts with the big disability charities many of which have turnovers of £100m plus:



This graph below shows that while a significant proportion of DPOs have seen an increase in income over the last 5 years, the majority have seen income stall or reduced. The self-reporting nature of this data also distorts this picture as DPOs that have closed or lost their staff won't be represented in these figures as they are likely not to have taken part in this e-survey:

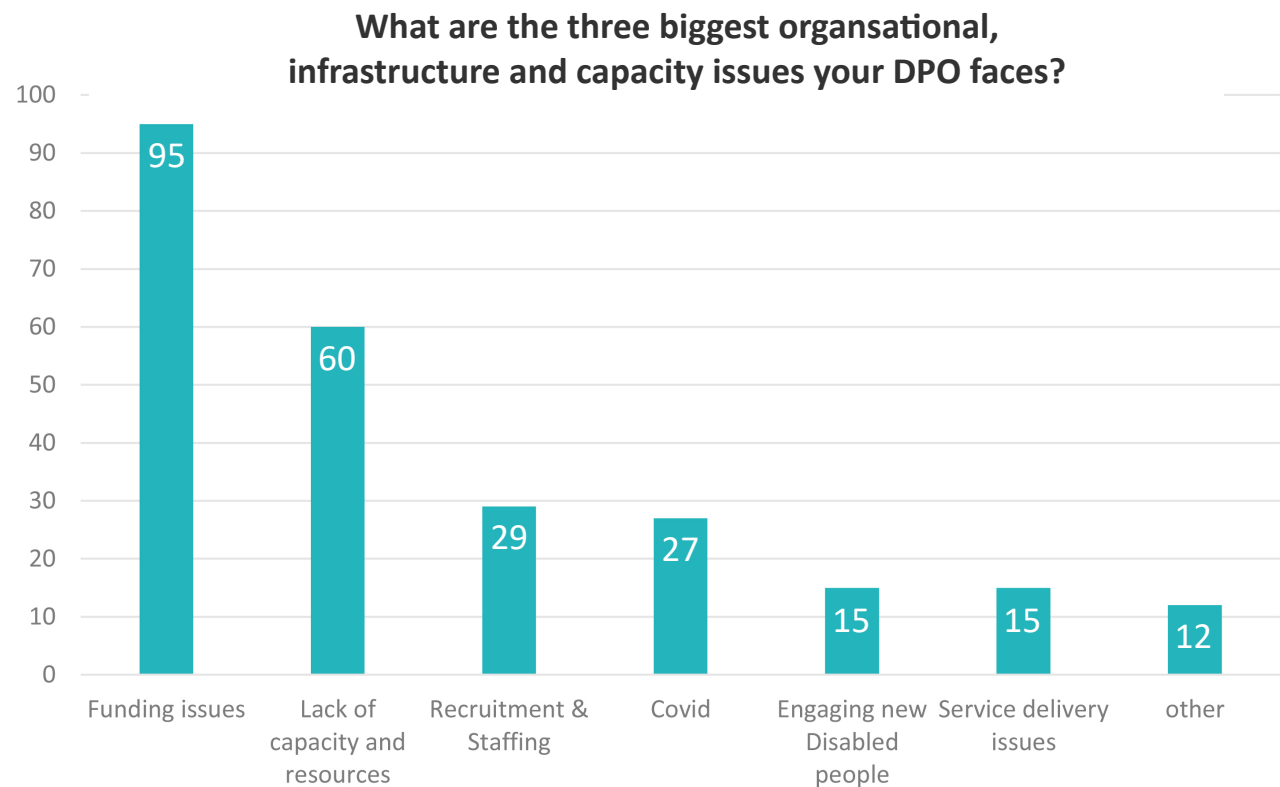


## Overview of DPO’s infrastructure, voice and policy needs

Our research focused on looking at the following 3 areas of DPO need:

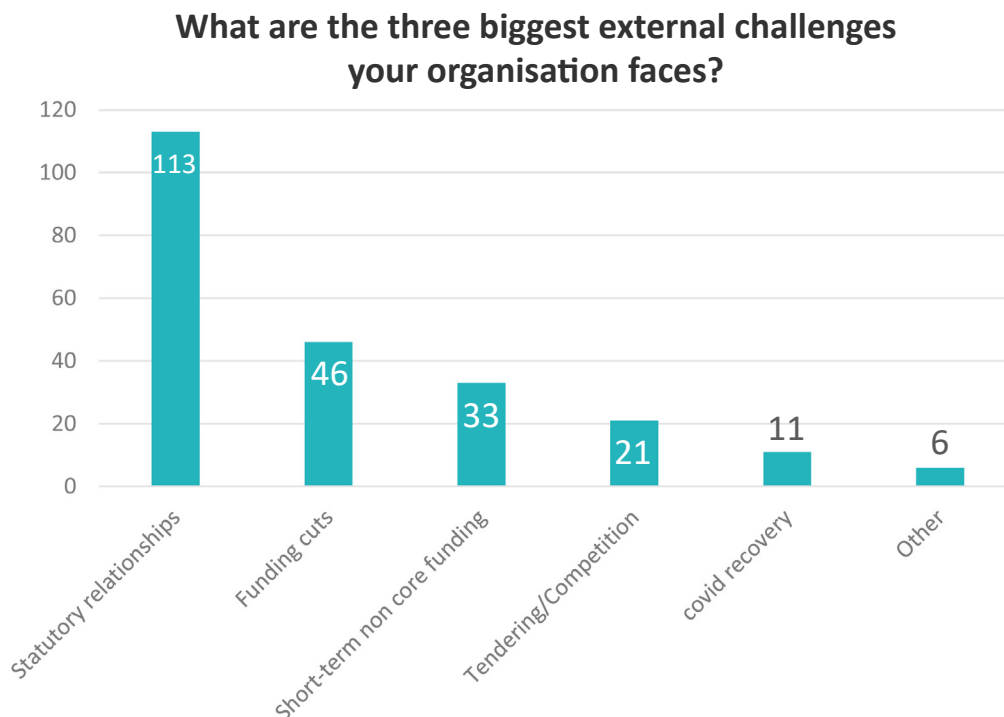
- organisational and infrastructure capacity building needs of DPOs at a regional and national level
- movement building needs of DPOs at a regional and national level
- voice, policy and representation needs of DPOs at a regional and national level

The graphs below illustrate some key findings across these three areas which are explored in more detail in section 2 of this report:

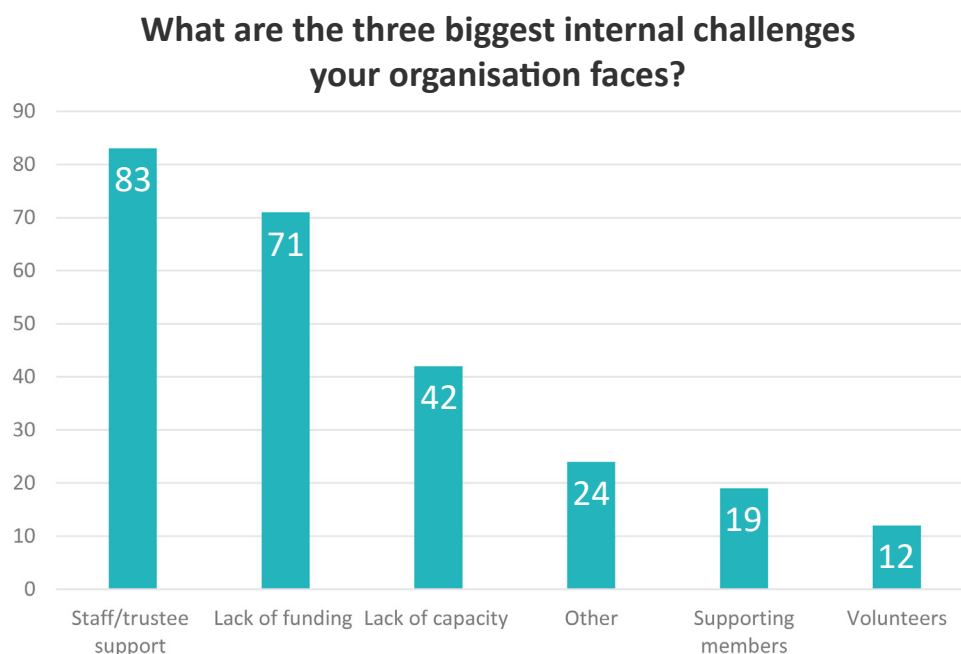


The above graph confirms the impact of funding issues on DPOs and its causal role in many of the other priority issues identified: lack of capacity and resources to meet the needs of Disabled people and to engage new Disabled people in DPOs. Difficulties recruiting Disabled staff were also identified as a growing issue of concern.



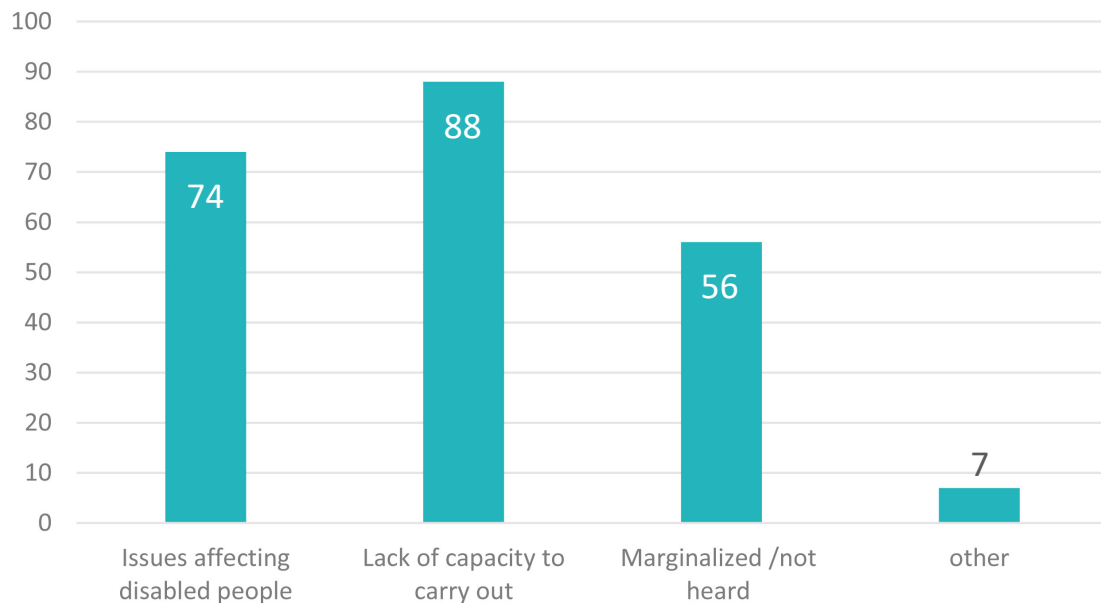


Deteriorating, and increasingly transactional and hostile, relationships with statutory bodies, most notably Local Authorities, was the overwhelming external challenge DPOs cited as their biggest external challenge followed by a range of funding issues including the dominance of short term, non-core project funding and tendering and procurement practices that systematically disadvantage DPOs.



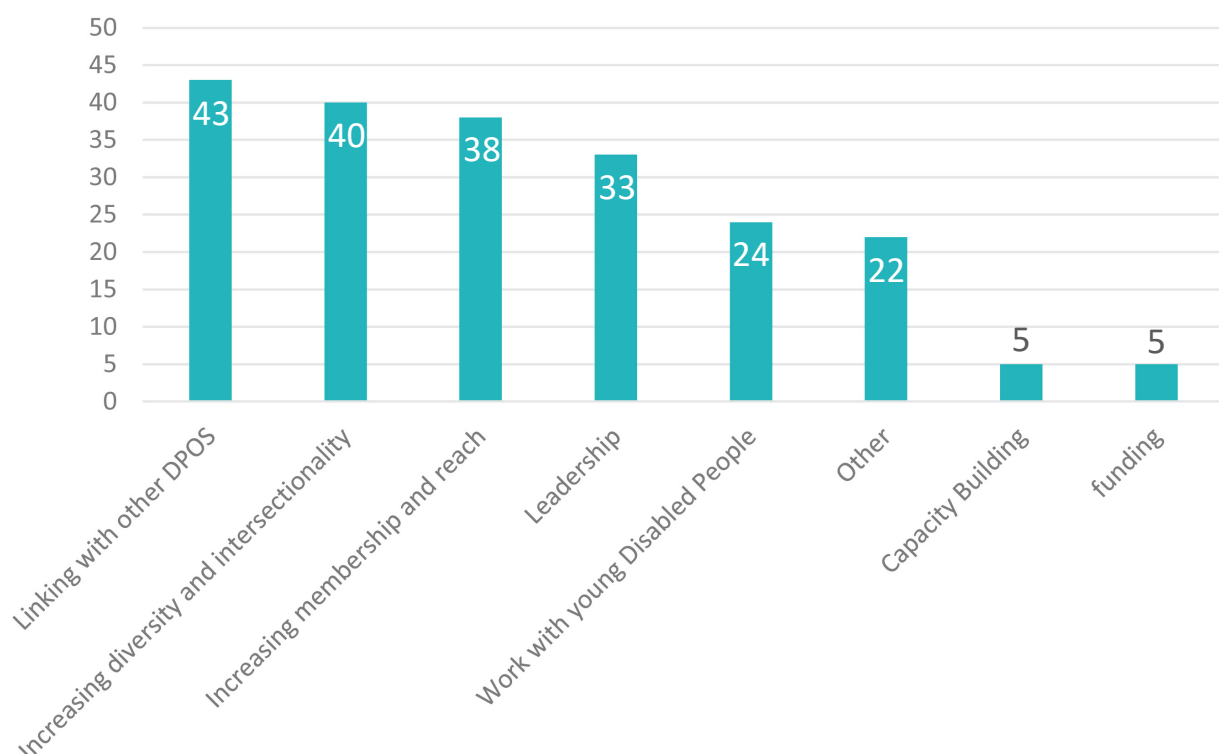
The consequences of funding cuts and lack of core, long-term funding also play a central role in internal challenges, with DPOs citing challenges to providing adequate levels of support to Disabled staff and Trustees, who often require additional management and HR support often not understood or recognised by funders, as the priority internal challenge.

### What are the three biggest voice, policy and representation issues your DDPO faces

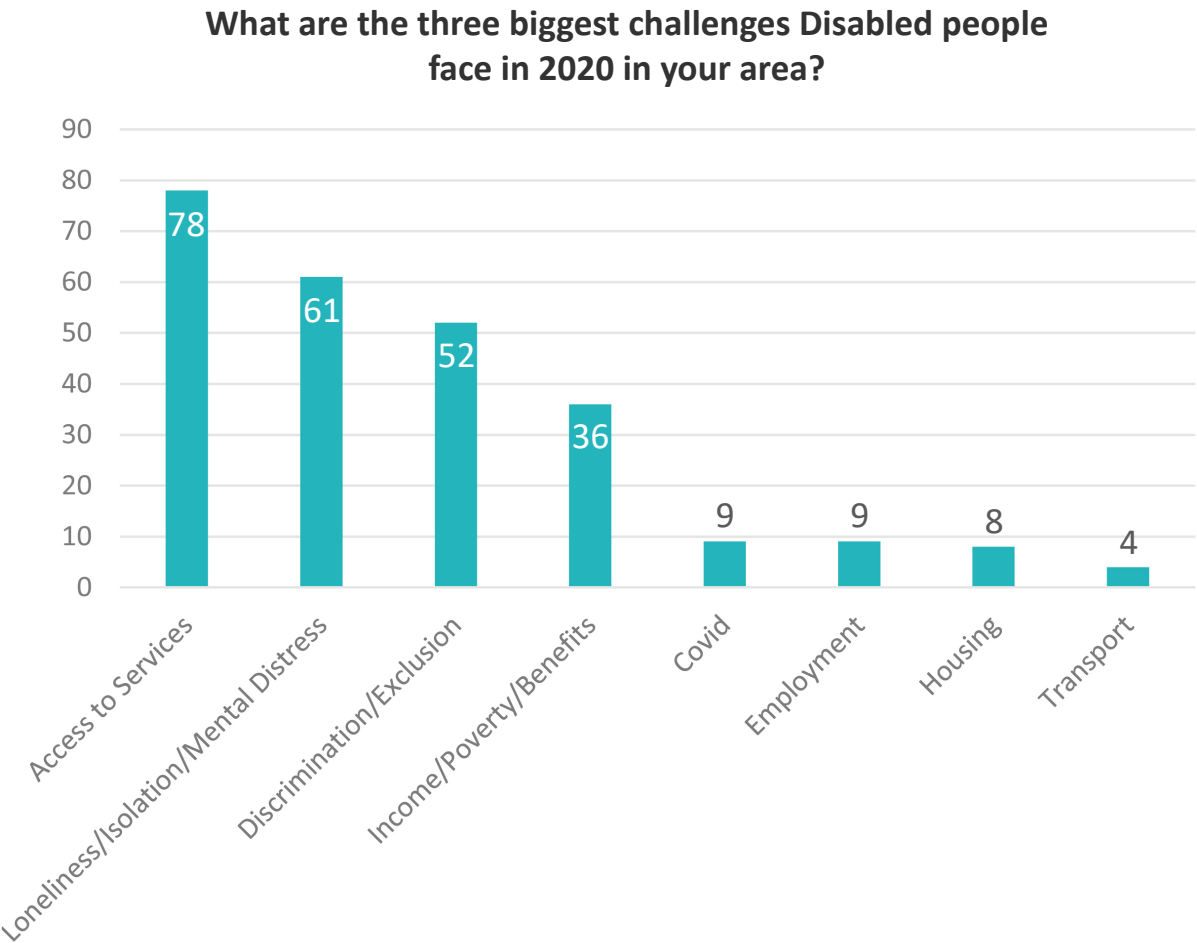


The increasing severity and complexity of Disabled people's needs and issues alongside a lack of capacity to voice or meet these needs were the priority voice, policy and representation issues cited by DPOs. This was closely followed by a shared view, amongst DPOs, that they are becoming increasingly marginalised by decision-makers with their voices often unheard or silenced.

### What are the three biggest movement needs your DPO faces?



DPOs reported widespread and increasing isolation from other DPOs. The need to re-connect with other DPOs and be part of the wider Disabled people’s rights movement came across strongly in the research with the need to link with other DPOs the highest priority for respondents. Being more representative of the diversity of the Disabled people’s communities, reaching and supporting more Disabled people, particularly those most marginalised and developing our next generation of leaders whilst providing better support to current leaders were all cited as key needs.



DPOs identified key on-going structural inequalities including difficulties accessing services and support, increased isolation, loneliness and mental distress coupled with exclusion, discrimination and rising poverty and inadequate benefits and income as top priority issues facing their members and service users.

# Section 2 - Research findings

## What Disabled People's Organisations (DPOs) do and contribute

DPOs have been at the forefront of the Disabled people's rights movement. As organisations run by and for Disabled people, DPOs have led the way in bringing about social change and in transforming the lives of individual disabled people. DPOs developed the rights based, social model understanding of disability and secured the introduction of anti-disability discrimination legislation at a national and international level. The understanding that disability is a human rights and social justice issue, rather than a medical or charity issue is a direct result of DPOs work over the last 40 years. DPOs also led the innovation and transformation in social care; away from 'one size fits all' dependency creating services, to personalised 'self-directed support' models that enable independent living, choice and control.



DPOs continue to play a vital role in enabling and supporting individual Disabled people and communities of Disabled people to access services and entitlements, challenge discrimination and exclusion and create a more inclusive and accessible world. DPOs do this by running a range of accessible & innovative community-based, peer-led advice, advocacy and support services and by bringing the 'added -value' of being user-led to the work they do. This added-value includes:

- expertise of lived experience: greater understanding and insight into Disabled people's needs; greater knowledge of issues; stronger relationship between the organisation and service user leading to more effective and better designed delivery
- peer support: Disabled people supporting each other builds resilience, skills, networks of support, participation & community capacity
- accessible: high quality & tailored support; higher take up by groups of

Disabled people unable to access mainstream / universal services

- holistic: DPOs meet the needs of the whole person resulting in greater positive impact and more cost effective interventions
- local knowledge, authentic voice & community asset: DPOs, as organisations set up and run by local Disabled people, have a better understanding of local issues, barriers and opportunities as well as local Disabled people's need and views. They tend to be more accountable to their community, have strong social model and Human rights values and increase Disabled people's participation in the wider community and in local decision making. DPOs often play a key role in making local services more accessible and actively enable public bodies to meet their Equality Act duties.

However, many of these gains and the added-value that DPOs bring have been compromised or eroded over the last decade:

“

We were set up by Disabled people but partly because the Local Authority wanted a strong User-Led Organisation. The Local Authority provided us with funding at start-up but has now cut and cut our funding.

South West DPO

”

“

Funding challenges are having a direct impact on the ability of DPOs to provide services, advice and support – in particular within the inclusive co-produced, rights-based model that is DPOs strength.

South Yorkshire DPO

”

## DPOs operating in England: coverage and gaps

*This needs to be reported!*



### Nationally:

Currently there is no funded national voice and policy organisation for the grassroots DPO sector.

Reclaiming Our Futures Alliance (ROFA) is a virtually unfunded grassroots DPO network with a wide membership of DPOs across all regions of England. Though it has an annual national conference and has made some important interventions over the last 5 years there is no funded organisation to carry out national representation and influencing functions from a DPO perspective<sup>9</sup>.

There is therefore an urgent need to co-ordinate and bring together regional DPOs to develop a collective and authentic voice for disability equality at a national level that will ensure voice and policy work reflects the needs of DPOs and Disabled people in each region.

### Regionally:

There are currently only two funded DPOs providing regional infrastructure in England: Greater Manchester Disabled People's Panel and Inclusion London (IL). There is a regional DPO in the South East, South East Network of Disabled People's Organisations (SENDPO), but SENDPO lost its core funding in 2016 and IL lost its core grant in 2017. SENDPO has continued to exist as an unfunded network on accrued funding, and the goodwill of more established members.

The importance of a regional DPO infrastructure was underlined by local DPOs:

“

Inclusion London is talking to funders about DPOs  
and the social model so all our bids can land  
without us having to provide an essay about what we do.

London DPO

”

<sup>9</sup> Disability Rights UK do carry out some national work but they sit between DPOs and the Disability Charities 'for' Disabled people and their membership is generally comprised of individuals, not DPOs, which reflects their history as RADAR a UK wide rehabilitation charity.



## Locally:

This research project has revealed large areas of the country that have no local pan-impairment DPO coverage. For example, the Eastern region has few DPOs across large counties, with Essex having lost its county wide DPO. DPO coverage in rural areas is more patchy than urban areas though in London there are also currently 10 boroughs that do not have a pan-impairment DPO and more with very limited resources and capacity.

“

DPOs in the South West of England have seen fewer closures than most other areas in the country, but 9 user-led groups have thus far been identified as having ceased operating in the South West in the past five years - itself a worryingly high number.

South West DPO

”

Despite the Prime Minister's Strategy Unit publishing the “Improving the Life Chances of Disabled People” strategy in 2005 with the goal that there should be a DPO in every area, this central and potentially transformational policy was never implemented<sup>10</sup>. When the Coalition Government, elected in 2010 ended the Putting People First strategy<sup>11</sup> and its targets for supporting the development of DPOs in every local authority, the strategic policy impetus was lost. This, together with the financial crash of 2008 and the subsequent decade of austerity, has led to DPO coverage across England being extremely uneven with large areas of the country, and hundreds of thousands of Disabled people, not served by a local DPO. Recent research estimates that 25% of DPOs have closed since 2015<sup>12</sup>.

<sup>10</sup> <https://core.ac.uk/download/pdf/4156824.pdf>

<sup>11</sup> <https://www.basw.co.uk/resources/putting-people-first>

<sup>12</sup> <https://www.communitycare.co.uk/2019/04/29/accelerating-closure-user-led-bodies-amid-care-cuts-creates-perfect-storm-disabled-people/> - <https://www.shapingourlives.org.uk/resources/external/news-23rd-may-2019>

The combined and conflicting priorities of meeting rising demand and need by Disabled people, while experiencing disproportionate funding cuts by Local Authorities, has resulted in a really challenging environment for DPOs, dominated by cuts to their funding and the implications this has had on DPOs capacity to support Disabled communities:

“

When we were set up it was policy to have a User-Led Organisation in every county – we see that has passed. Local Authorities have shrinking staff and a massive turnover of staff. Consultation has become a tick-box exercise. We have consultations with the Local Authority and with the Police - our members are like ‘what’s the point in this?’ - we have gone to a great deal of effort and we don’t get any feedback.

”

South West DPO

Particular gaps have been identified in the DPO sector including the closure of many DPOs controlled by people with learning difficulties. The gap left by the closure of many People First groups has allowed organisations, not accountable to people with learning difficulties, to mimic the rhetoric of self-advocacy and self-empowerment without handing control of organisational decisions or activities over to their users:

“

I can tell you what I’ve learned from people; which is that when People First closed, a lot of people were really devastated. The whole point of self-advocacy is that it’s a group of people supporting each other to speak out and against things, to have confidence to say ‘I want my life to be the way I want it’. When it fell away, it led some people to become so isolated that what happened to them was really grim.

”

South West DPO

## Intersectional Issues:

Intersectionality is an analytical framework, developed by the Black feminist Kimberlé Crenshaw, for understanding how race, gender, class and other systems of oppression “intersect” with one another to create different modes of discrimination and erasure for groups experiencing multiple oppression, for example Black Disabled people.

DPOs saw taking a more intersectional approach to the work they do as a priority issue in order that they can better reflect, understand and represent the full diversity of the Disabled people they serve. However, few had the capacity to take the specific and comprehensive actions needed to improve intersectional representation and approaches:

“

We want to be inclusive and representative of everyone.  
Practical support around this would be helpful.

We are mixed in our racial background and impairments;  
some we need to address.

We have a low number of LGBTQ+ members.  
We need to address intersectionality.

London DPO

”



Intersectional specific DPOs are very few in number and are chronically under-supported and under-funded:

“

It is very difficult when you're running an organisation  
to have no networks or support.  
Many organisations can't get to be part of a movement  
to support their development.

BAME DPO London

”

“

There is a lack of understanding about  
what intersectionality means within the DPO sector  
but also from funders and other external groups.

London-based Women's DPO

”

Often the result is organisations closing:

“

This is gross negligence towards BAME disabled people.  
Organisations have gone, have not flourished internally  
because they don't have financial resources.  
Some groups have disappeared  
because they don't have the relationships and networks  
– not part of any forum.

London based BAME DPO

”

Most DPOs recognised the need to improve and do better on intersectionality.

### Here is a summary of issues raised:

- There was a strong desire from participating DPOs to better reflect the diversity of the communities they work in, but most lacked the capacity to build strong intersectional links and relationships across their organisations.
- Some organisations were strong in one area of diversity but weaker across other intersectional issues for example some DPOs in Bradford said they were strong on Black, Asian and Minority Ethnic (BAME) representation across their organisations, but need to do more work on including people with learning difficulties and Disabled members of the Lesbian, Gay, Bisexual, Trans, Queer + communities.
- Many identified the need to meet together regionally to learn from each other and build their capacity across intersectional issues.
- Structural inequality framed these discussions and a recognition that funding is required to address intersectional issues, increase diversity and inclusion in the DPO sector at both regional and national levels.
- A lack of understanding about what intersectionality means and how to use a more intersectional approach in DPOs and across the wider public and voluntary sectors

One DPO, ALLFIE, has set up a Disabled Black Lives Matters (DBLM) group in response to the emergence of BLM internationally. This group is building peer support and carrying out key advocacy work as well as bringing younger Disabled members of the BAME community into ALLFIE and in turn the wider DPO sector in London.



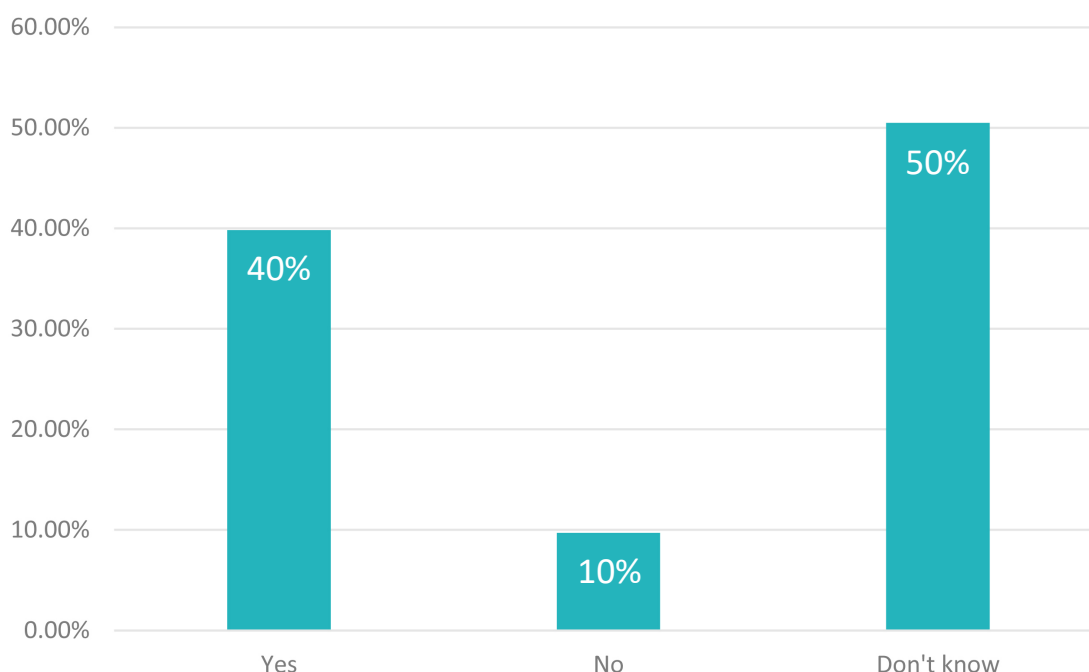
## Funding Issues:

Funding unsurprisingly emerged as one of the most fundamental challenges for almost all organisations which took part in the research. The rapidly changing and complex funding environment together with a decade of funding cuts has impacted on all areas of DPO work.



The e-survey responses to the question about the closure of DPOs in their areas over the last 5 years detailed in the graph below reveal a large number of DPO closures with 40% of respondents saying they knew of DPOs who had closed in their region and only 10% of DPOs reporting no closure of DPOs in their region. The response also revealed the increasing isolation of DPOs from each other and fragmentation of the sector with over 50% DPOs saying they did not know if other DPOs had closed or not.

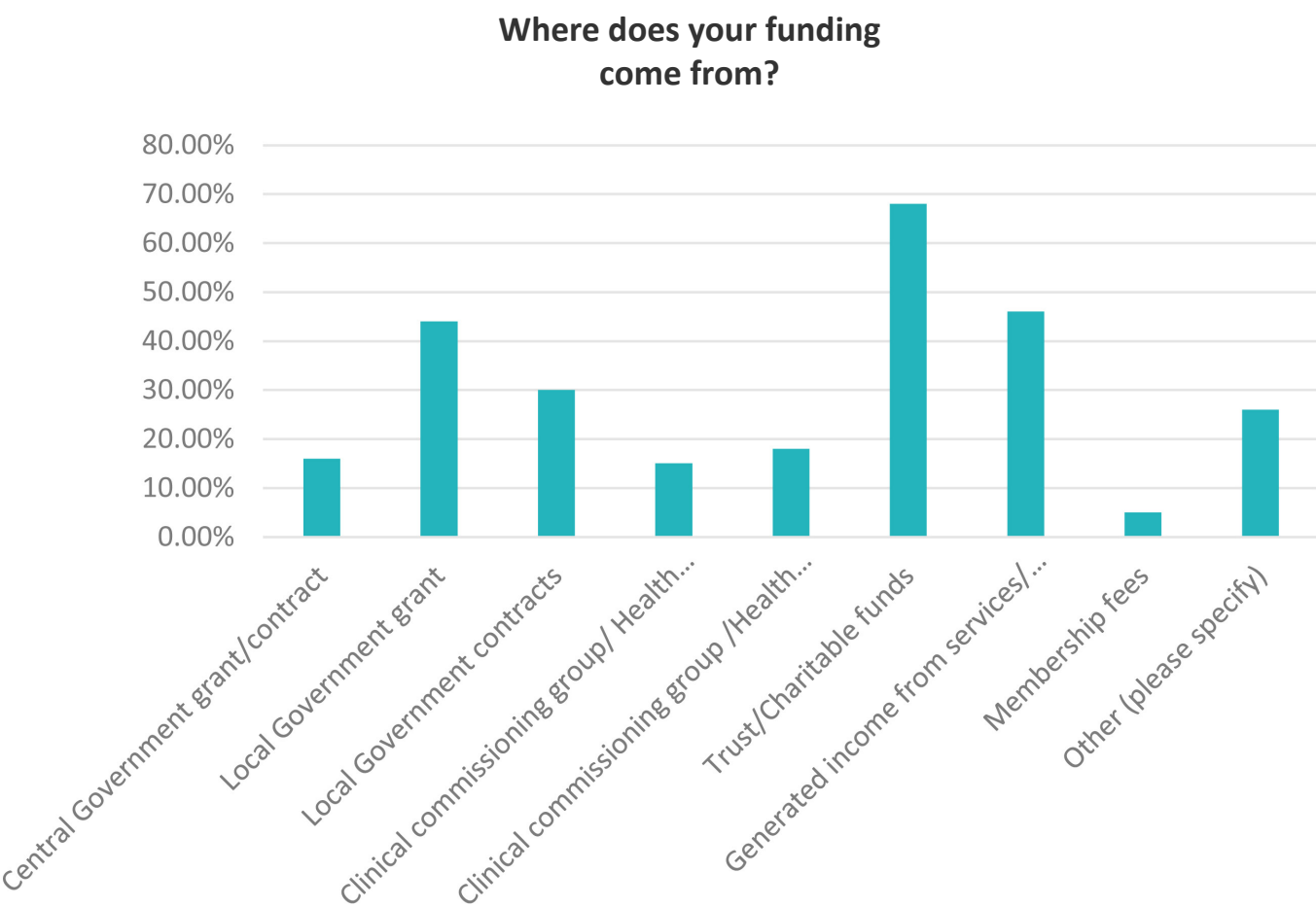
**Have any DPOs closed in your area over the last 5 years?**





The graph below illustrates the wide variety of sources of funding that DPOs secure. This can be seen as a strength with a diversification of funding leading to greater sustainability. However, the dominance of short-term, project based funding, alongside funding cuts, reveals a precarious picture. The reduction and/or lack of core funding, largely due to austerity and cuts to Local Authority budgets means that DPOs existence is often ‘hand to mouth’ with little ability to carry out long term planning or invest in staff and service development.

Contracts with public bodies are subject to regular re-tendering processes in an increasing demanding cycle of a ‘do more for less money’ funding environment. Contracts that were the won and awarded to DPOs have also been the target for predatory disability charities and ‘for profit’ businesses try to undercut DPOs.



## Funding cuts: impact of austerity on DPOs

Austerity cuts, primarily passed down from central government to Local Authorities and onto DPOs (and the wider third sector) emerged as the major source of funding problems for DPOs.

“

Set up in 2010 – we were working really close with the councils  
- lots of funding and support in kind from them,  
suddenly [we] have been completely cut adrift from the Local Authority.  
Some contract work, but that means that [we] are delivering at a loss,  
so [we] now have to say no to contracts.

Austerity and huge cuts to statutory and community support  
is creating deeper poverty, exclusion and distress  
and rising demand, and complexity of demand, for DPOs.  
Local Authority/funders cuts, taking services in-house  
and the reduced involvement of DPOs in/delivering services  
are having a cumulative impact  
on their financial situation and sustainability.

”

South West DPO

Austerity cuts have resulted in an erosion of the choice and control of Disabled people using social care and direct payments services. Many Local Authorities have ended contracts with DPOs and taken DPO-run services in-house. Norfolk is a good example where the direct payments support service was taken away from the local DPO and is now run by the County Council. Like many Local Authorities, Norfolk then imposed discriminatory charges for social care, taking money from people's benefits. This resulted in a judicial review, which found in favour of Disabled people<sup>13</sup>.

<sup>13</sup> <https://www.bailii.org/ew/cases/EWHC/Admin/2020/3436.html>

## Failure by funders to understand the added-value of DPOs

There is a growing failure by funders to understand the added-value / USP of DPOs as user-led organisations and consequently a strategic failure to prioritise funding to DPOs. It was strongly noted that big charities 'for' disabled people find it easier and have the dedicated fundraising teams to be in a much more advantageous position to win contracts. Small DPOs have experienced being cut out of procurement and tendering processes, with large organisations benefiting from this:

“

It is easier [for the Local Authority] to be able to deal with large organisations rather than multiple small organisations

Difficult to acquire funding if they have a ceiling  
– e.g. 10% of your income

Funding was refused because the organisation is 'too small'

East Region DPO

”

## Dominance of short term and restricted project funding

What statutory funding available is almost invariably short term, restricted project funding that prevents DPOs from building sustainability, developing services and investing in staff:

“

The retention of staff is hard as funding is short term –  
people don't know if they have a job.

North West DPO

”

“

Contracts now are all 1 year – there's no stability -  
bidding as soon as you get into the swing of delivery.  
It leads to very high staff turnover.

South West DPO

”

## Lack of core long term funding

The lack of core funding was highlighted again and again as a major barrier to networking and movement building locally, regionally and nationally:

“

There does seem to be a bit of an obsession  
with funding projects instead of core.

It's like...well...what's so wrong with core?

You know, you need the people, you need the facilities to do the stuff

North East DPO

”

“

It is hard to maintain relationships and attend meetings  
as there is no core funding, just project funding.

Without more funding it was hard to manage expectations  
of partners who were used to being able to do more.

South East DPO

”

Systemic lack of core long term funding hinders DPOs ability to deliver accessible, holistic services and to carry out the outreach and voice, community and movement building work needed:

“

Financial uncertainty is having an impact on DPOs ability and appetite  
to recruit disabled people as trustees, employees and volunteers.

This in turn is having an impact on DPOs ability to be confident  
they represent the diversity of disabled people in their area

and can credibly deliver representation of disabled peoples' voice  
to Local Authorities and other organisations.

South Yorkshire DPO

”

“

Core funding is critical yet hard to get—  
often funding is related to specific projects.

London DPO

”

The complexity of trying to meet rising demand at the same time as the loss of core funding is illustrated by this DPO:

“

The thing with (our DPO) as with a lot of other disability organisations is that it sort of bellows, new projects come up as well as new funding streams being introduced so the organisation grows to meet those needs and when those projects finish the organisation shrinks again, were constantly growing and shrinking again, which is so hard to maintain. The difficulty and lack of ability to get a hold of any core funding makes it incredibly hard to secure your base as an organisation; to maintain and support and to anchor it, from which you can then grow in a consistent way

”

South West DPO

A DPO in the North West summed up the feelings of many DPOs:

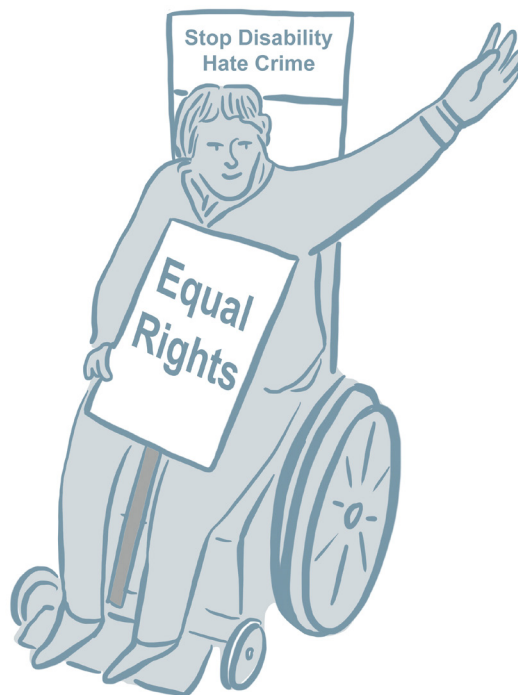
“

We need an acknowledgement at government and other levels, that DPOs are the best to support Disabled people so it would be nice if they gave us some core costs. If you could have a 10 year core costs grant to let you get on and do your stuff, you could then fundraise more for services

”

North West DPO

There is a linked need to the growing challenge of securing funding for ‘bread and butter’ core information, advice and advocacy services and community development work, which are a critical safety net to help ensure Disabled people can access entitlements and essential services:



“

It's not just advocacy needed – people need advice services. Especially around race and disability discrimination. Difficult to monitor that. Lot of unmet need externally – brought to our attention by individuals.

”

BAME DPO London

### Lack of funding to cover full costs of running a DPO

The lack of funding to cover the full costs of running a DPO including meeting the additional and often complex access and support needs of staff, members and users was a key challenge reported by nearly all DPOs:

“

Not having full costs of running a DPO, because of the lack of core funding, is having a devastating impact on the sector. There are additional HR, access, training and support costs that are stressful, take lots of time to do but are never funded.

”

DPO South West



## Failure to fund longer term community and movement building

There is also a long term and increasing failure to fund community and movement building, which is the glue that keeps DPOs together and the engine for creating real change. This point was highlighted by a BAME led DPO:

“

Sustainability of issues long term –  
what happens is that BAME disabled people are seen as projects.  
Resources are for projects – when the project comes to an end  
so does the support.

BAME DPO London

”

“

There's a shock of the new in that funders tend to be interested in niche,  
specialist, flavour of the month projects. You need DPOs  
doing the same things in different places that meet people's needs.

I see some specialist things coming out

that many Disabled people can't access.

There is a presumption that the basic stuff has been sorted, but it hasn't.

It's not one or other but otherwise you can't build the sector up.

The things that people tell us they need are not very sexy  
but they are very needed. I am exhausted by innovation.

North West DPO

”



## Contract culture of the 'cheapest bidder wins'

DPOs reported that they are operating in an increasingly competitive landscape for access to ever-shrinking levels of funding.

A dominant tender and contract culture of the 'cheapest bidder wins' in turn results in services that are chronically underfunded and creates an unfair and often hostile environment of competition that consistently disadvantages DPOs. Contract culture favours large commercial organisations and the disability charities, led by non-disabled people, who often compete against local DPOs in the tendering process.

“

We are constantly tendering against big national organisations.  
We are a little tiny organisation in Devon.

We do sometimes win (like our Advocacy service)  
but we are up against big organisations with big marketing budgets.  
National tenders - not county-wide.

It is nice to join up with others, but it is frustrating when we have local  
knowledge, but lose to the marketing budgets of Serco and the like.  
Infrastructure organisations, like CVS and the like, are who people go to,  
so people are speaking for us rather than us speaking for ourselves.

South West DPO

”

“

The (DPO) sector isn't seen often as an equal partner.  
Sometimes, they want to hear what you have to say,  
but then if they don't like it, they just ignore it.

And that can get in the way of building capacity because  
they're looking for what they need, they're pushing us, we push back.

So, they end up being...quite confrontational sometimes...  
you can be doing things, and they say "well actually, we don't want that,  
we want this", but the people we work with say "no we want this".

North Yorkshire DPO

”

Unfair competition and scarcity were also keys issues, exposing the lack of a ‘level playing field’ for DPOs when it comes to tendering:

“

Over the past couple of years, funding has become more predatory and competitive, especially now funding pots are smaller and funding requirements have increased.

Midlands DPO

”

Competition from local, regional and national non-disabled led organisations, including the big disability charities, who in turn have undertaken a more aggressive approach in terms of price cutting, has been difficult for DPOs to deal with. It was expressed that local DPO’s found this frustrating and challenging when national organisations with no local knowledge are successful in tenders:

“

...national charities have come into the space and taken funding from local organisations.

Midlands DPO

”

“

...for it then to go to a national organisation, really was a bit of a kick in the teeth.

North East DPO

”

Meeting the full cost of access for Disabled people also affects DPOs ability to win funding bids that are awarded on price:

“

Because we support people who have access needs – BSL and captioning for example – our funding bids are more expensive, because we need to spend money on Communication support. The lack of understanding of the need for communication support is a huge issue. It is not just for d/Deaf people but people with Learning difficulties and dementia too.

South West DPO

”

## Reduced funding to meet access needs

Reduced funding means reduced capacity to meet the access needs of the Disabled people DPOs serve:

“

(W)e ended up with little-to-no money or staff time to hold large, public consultations with Disabled people.

There was an argument, I think last year, when I was going to a disability event.

I had to ask for an interpreter,

someone else had to ask for a speech to text translation; and someone in the audience said: ‘we should not be asking for these things, these things should be given to us.

They should be there already as part of the plan.

You’re talking about disability and we should be part

of that disability movement.

You’ve put a ramp outside, why aren’t you providing interpreters? Why do we have to ask?

”

South West DPO

Without adequate funding to meet access needs DPOs are struggling to maintain current levels of accessibility let alone improve access provision to ensure the most marginalised groups of Disabled people can access their services.

Lack of funding for access can cause DPOs to be perceived negatively by the communities they serve and lose the invaluable trust they have built up over many years with their membership.

## Rising demand and diminishing resources

DPOs reported growing demand for services and growing complexity of needs of Disabled people coming to DPOs for support. Alongside the on-going need to support Disabled people to access services and entitlements and challenge exclusion and discrimination. DPOs reported:

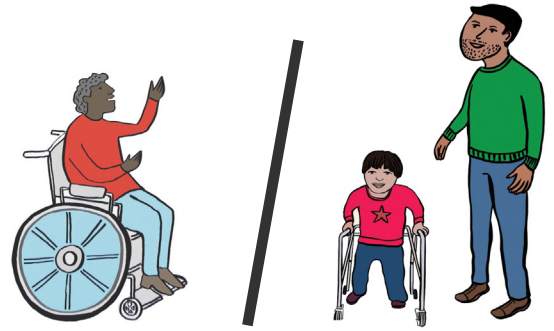
- increased and deeper poverty, debt and destitution issues
- increased need for welfare benefits advice and representation
- increased need for social care and housing advice and advocacy
- increased need for advocacy services for people experiencing mental distress
- increasing numbers of Disabled people are no longer eligible for statutory support and are therefore cast adrift from essential support and entitlements
- a range of Covid-19 related needs including digital exclusion from online resources, rising hate crime and increasing employment discrimination.

Tackling these issues and trying to meet these needs at the same time as managing the funding issues detailed in this report are incredibly challenging and stressful for DPOs and individual staff working within the sector.



## Fragmentation and Isolation of DPOs

Because of the gap in regional and national infrastructure, local DPOs currently do not have any means of communicating and networking with each other regionally and don't have a funded voice nationally<sup>14</sup>. This was highlighted by the finding in our e-survey that 50% of DPOs did not know whether other DPOs in their area had closed or not.



The lack of infrastructure support was acknowledged as a key area of need by DPO research participants, as was the view that the right infrastructure could bring about transformational change. Sharing expertise and experience with other DPOs and creating opportunities to collaborate and develop a collective voice of Disabled people could bring about real change and help address the structural power imbalances between DPOs and funders/decision-makers:

“

.....we started a forum for smaller charities (DPOs) to share information and come together to improve services as a whole rather than individually which has worked well but would like to see something like this on a regional level.

Midlands DPO

”

The lack of opportunities to network with peer DPOs regionally and nationally leaves the sector underdeveloped and exposed:

“

we need to try and support each other because being an independent group is good but there is strength in numbers. We need to preserve independence, but we need to be able to reach out to other DDPOs for advice, support and especially in London, shared working and projects.

London DPO

”

<sup>14</sup> ROFA has 'punched above its weight' as an unfunded network of DPOs across England and it has made powerful interventions in policy areas like independent living, Disability benefits, Covid-19 and researching the needs of DPOs.



“ It was universally agreed that the DPO movement in the South West is not well coordinated, with extremely limited collaboration between DPOs in the region. There was a feeling among participants that DPOs had become inward looking and that organisational cultures had prevented DPOs from seeing themselves as part of a wider movement. ”

South West DPO

“ We need regional and national infrastructure to support DPOs. We need to bring user led organisations together into a block. Independent organisations but a national structure – also a way of keeping funding within user led orgs. ”

London DPO

A BAME led DPO commented:

“ Internally – very difficult when you’re running an organisation to have no networks or support. Many organisations can’t get to be part of a movement to support their development. ”

London based BAME DPO

“ DPOs need to work a lot closer together – champion the cause together. Needs to be space for BAME disabled people’s organisation to grow, network, etc – we don’t have the financial resources to have the capacity to do this. ”

London BAME DPO

It wasn't always this way. When the British Council of Disabled People (BCODP) was a thriving network of DPOs and received core funding it was able to create joined up partnerships, regional networking, provide a national voice and develop projects and innovate. This included establishing the National Centre for Independent Living (NCIL) and the Disability Studies courses at the University of Leeds. Since its demise, DPOs at a regional and local level have very few opportunities to build a collective voice, share peer support approaches where DPOs can share information, problem solve and advocate together and in turn, develop and innovate.

“

Gosh, I think most days I'm pretty disheartened. There's been a whole heap of things, obviously economic things are major things. I think most disabled people are worn down by the system, benefit assessments, and discriminatory government policies; I think the energy to fight for change has kind of dissipated. There's so much that's so awful, that I don't think people know where the heck to fight. Before, there were some very specific campaigns that people joined in on, but there's so much now that people don't know where to start when it comes to campaigning.

”

South West DPO

This research and the NLCF funded Disability Research on Independent Living & Learning (DRILL) project are the first opportunities for DPOs to collaborate together on a significant scale on research, capacity building and development issues since 2011.

To summarise the currently fragmented DPO sector stops DPOs sharing, learning and working together it:

- severely restricts potential for joined up partnership service delivery between DPOs
- undermines collective voice and peer approaches where DPOs can share info and bring about change
- prevents DPOs problem solving and advocating together
- undermines innovation in service development, policy and voice work



Where this regional function does exist currently in the South East, North West and London, the DPOs interviewed valued this resource and spoke about the positive impact it has on their ability to serve their members and become more sustainable. This was emphasised in all the London focus groups, particularly valuing policy focussed projects, the creation of training and funding opportunities and support with work on intersectionality:

“

We sent one of our staff to some Inclusion London training on community journalism – so we could get more authentic stories from local disabled people.

We got a grant to support that work.

We are now training 20 disabled people in 6 training sessions in journalism techniques and sharing stories.

We are using low cost tech, e.g. mobile phones, to do this.

We have a grant for a freephone number people can just put experiences on – we can then analyse data and use it. We are going to have a co-production group with the council to analyse data.

”

BAME DPO London

This was also particularly important during Covid-19, when joint research informed voice, policy and rights campaigns to overcome the discrimination faced by Disabled people in the pandemic. ROFA/Inclusion London were also able to negotiate a £1.5m UK-wide Covid-19 DPO Emergency Fund with the National Emergency Trust (NET):

“

Inclusion London training has been hugely helpful, we did well in COVID emergency grants, which we found out about from Inclusion London.

London DPO

”

The NET programme, like this research, was delivered by and through a network of 8 regional DPOs across England coordinated by ROFA/Inclusion London.

## Marginalization from Decision Making

A clear picture emerging from this research is of systemic marginalisation of DPOs, by the UK Government at a national level and increasingly at a local level by Local Authorities.

There is currently no effective engagement between the UK government and DPOs nor is there any central government financial support to enable DPOs to take part in engagement and co-production – all of which are governmental duties under the UN Convention on the Rights of Disabled People (CRPD) . This lack of engagement was highlighted by the UN Disability Committee as an issue of particular concern in its periodic review of the UK in 2017<sup>15</sup>.

This experience of marginalisation at a national level is also reported by DPOs at a local and regional level, with many DPOs reporting feeling increasingly disconnected and marginalised from their Local Authority and other statutory bodies:

“

I think there is a lack of understanding about what co-production really means, around what the social model of disability really means, around what equality really means within our statutory sector partners.

London DPO

”



Relationships between Local Authorities and DPOs are becoming increasingly transactional and contract driven with Local Authorities demanding ‘more for less’.

<sup>15</sup> <https://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2FPPrICAqhKb7yhspCUnZhK1jU66fLQJyHlkqMIT3RDALiqzhH8tVNxhro6S657eVNwuqlzu0xvsQUehREyYEQD%2BldQaLP31QDpRcmG35KYFtgGyAN%2BaB7cyky7>

## Relationships with Local Authorities

DPOs are reporting an increasingly hostile stance from Local Authorities towards DPOs. This includes questioning DPO's advocacy and voice role if they are also delivering council contracts with some DPOs losing contracts because they challenged Local Authority policymaking. As a result fear of losing funding and support from Local Authorities for speaking out or challenging is a very real issue for DPOs:

“

Our organisation was very afraid about campaigning in fear of alienating the LA. We had an arm's length relationship with a user led support group, we created support for them but didn't align our name to it in case we stood out.

”

London DPO

There has also been an erosion of understanding around all aspects of disability equality by Local Authorities. Austerity cuts have also eroded capacity and continuity in Local Authorities:

“

the constant turnover of staff in the LA means it has been difficult to build a relationship as it is difficult to know who and where to go.

It feels like the local authority does not take us seriously...

the relationship depends heavily on the personalities of the individuals.

”

Midlands DPO

The silencing of Disabled voices by Central and Local Government is one of the most concerning changes that has taken place over the last decade:

“

There's a culture of 'don't say too much'.

There is caution around what we can ask the LA.

People are scared to challenge.

”

London DPO

“

Developments over last 5 years and the reduction of DPO contact with LAs is reducing our ability to retain contact or maintain relationships with the decision makers and ‘local champions’. This in turn is having a negative impact on the ability of DPOs to represent disabled peoples’ voice and be confident that they will be able to secure future funding or be involved in delivering/supporting local services

”

South West DPO

“

High staff turnover in LAs/services is of significant concern – in particular with replacements not always recognising the value of DPOs, considering ‘voluntary as free’, not willing to fund engagement and co-production work and involving DPOs in a ‘box ticking’ as opposed to meaningful way.

”

London DPO

There are particular issues facing small and largely unfunded DPOs:

“

We only have funding from DPO and user-led funds. Obviously, we’re independent, but it is clearly harder without any funding. The benefits include not being afraid to criticise any major organisation; as we don’t receive any financial support from them, we therefore don’t have to worry about losing any funding. We are, however, in a bit of a catch-22 situation: although we’re all volunteers, the downside is not having the funding to campaign more effectively; which in turn could be a barrier to receiving funding from any source we may wish to criticise in the future.”

”

South West DPO

## Internal Issues

### Increasing Difficulties Recruiting Disabled Staff

Many DPOs reported increasing problems recruiting Disabled staff:

“

It is hard to get CEOs and Managers with lived experience – user-led organisations ideally are led by a CEO with lived experience. Disabled people just don't have the opportunities to build those skills to the extent that non-disabled people do.

”

South West DPO

The reasons for this are complex. They reflect a matrix of structural inequalities that mean Disabled people are less likely to have the opportunity to gain work experience, qualifications and carer progression; coupled with employment barriers, attitudinal and physical barriers; together with cuts to Disabled peoples social care/ independent living support. The following key issues have been identified in the research:

- Lack of work experience and opportunities to gain specific skills and experience
- Lack of social care support that increasingly means Disabled people with high support needs are not able to be in paid employment
- DPOs increasingly unattractive terms and conditions including short term and /or precarious contracts, flat organisational structures with little career progression and high workload, mean DPOs are not an attractive employer for many people
- Lack of entry level jobs in DPOs
- Lack of funding for apprenticeships and traineeships in DPOs
- Lack of training, support and mentoring budgets
- Internalised oppression/lack of confidence that mean very many Disabled people feel they are not good enough (this is especially the case in leadership roles)
- System wide problems with Access to Work due to cuts to budget and eligibility criteria

## Little Capacity to Support Current and Future Leaders

The research revealed high levels of concern about many linked leadership issues for DPOs ranging from lack of capacity to support current leaders to the need to create new pipelines for developing future leaders.



### Challenges facing current leadership in the sector include:

- Age profile of people in DPOs is increasingly older people nearing retirement
- Flat organisational structures with overload and multiple roles and functions in one CEO/ Director post whose role often includes: HR, finance and payroll; funding/fundraising; monitoring; project management; line management of staff; office management; IT lead; office caretaker as well as strategy and representation.
- Lack of time and space to build capacity to strengthen strategic engagement, building relationships with Local Authorities, carry out lobbying/influencing nor carry out the strategic planning needed to develop and sustain organisations
- Lack of training, mentoring, secondment and professional qualification opportunities for current leaders
- Lack of capacity and resources to carry out succession planning to ensure DPOs are able to recruit, induct and train next generation of Disabled leaders
- Increased risk of burn out which has been exacerbated by additional demands of the pandemic
- Losing experienced leaders to the consultancy world

### Challenges facing current leadership in the sector include:

- Lack of resources to provide accessible and rights-based mentoring, coaching and training opportunities to support potential and emerging leaders
- Lack of entry level jobs to get Disabled people in paid posts within DPOs
- Flat organisational structures with few opportunities to develop a career pathway



- No funding for apprenticeships and traineeships
- Very limited connections to younger disabled people
- Relevance and attractiveness of DPOs to younger Disabled people
- Losing Disabled people to better funded / less demanding and stressful sectors

### Challenges facing developing and supporting future Trustee leadership of the sector include:

- Difficulties recruiting Trustees, especially young and Trustees with intersectional experience and from specific impairment groups
- Lack of capacity to induct, train and support Trustees
- Many organisations run by people with learning difficulties are at threat or have closed as a result of the lack of adequate support for Trustees

“

where will those leaders come from? The next generation of leaders is going to be the difference between us surviving or not surviving.

North West DPO

”

“

DPOs are struggling to recruit and retain disabled trustees, employees, volunteers and members.

This is making their existence as organisations composed of and led by disabled people increasingly difficult – especially if their aim is to be 100% DPO – and raising concerns that their USP is under threat if they are to remain sustainable.

However, the composition of boards, staff/volunteers and members that are disabled seems to be falling and it is evident this situation is at risk of continuing.

South Yorkshire DPO

”

“

Composition of DPOs is increasingly of older disabled people and there is significant concern that the perception of DPOs reflects this. There is also concern that there is a widespread perception that DPO membership/focus is about people with physical impairment with the consequent that many disabled people (especially younger people) are not attracted to join them – often joining other (often non DPO) impairment specific groups or no groups at all.

”

South Yorkshire and Humber DPO

Support for leaders within DPOs was identified as something many participants would like to see more of. People in leadership staff positions in DPOs are often a “catch all” of what should be multiple funded roles:

“

As manager, I’m sort of manager, finance manager, HR, fundraiser, and lots of charities will recognise that...I do all of those things. So really it was down to me. The only challenge was how long I could keep going without falling over

”

North East DPO

Overloaded leadership results in a stretched capacity, limiting space for growth, innovation and development. Core, long term funding would be instrumental in giving space to leaders to be able to focus on the delivery and to build capacity, rather than constantly seeking additional funding and dealing with HR and finance/admin. It would also create the space and capacity to strengthen strategic engagement, building relationships with Local authorities/councils and carry out lobbying and influencing work. Succession planning was identified by some DPOs as a key issue with regards to leadership:

“

People are in posts for a long period of time and find it difficult to think about the next stage and who you might be recruiting to fill those gaps, I think succession planning is a big deal.

”

South West DPO



Part of the difficulty in succession planning is the lack of flexible, core funding available, which allows for the development of skills, experience and management skills in other staff. There also needs to be a stronger mechanism and funding available to develop career pathways within DPOs. This lack of career pathways often means younger Disabled people look outside the movement for opportunities to develop.

“

**I wish there was a fast-track disability trustee support service!  
In the non-disabled community, you have people who have worked  
as director of a FTSE100 - we have far less experience  
in the disabled community**

”

South West DPO

Despite all these challenges DPOs continue to be places where Disabled people often move from service user to volunteer to Trustee to paid employment; developing skills, experience, confidence and a shared positive sense of collective identity:

“

**We have advocacy services and mentoring services.  
Programmes where people are able to follow how to  
become activists and changemakers in their communities.**

”

BAME DPO London

“

**We support our members to go from being isolated to  
becoming active, a model of active citizenship if you like...  
We have quite a good record of people being users of the organisation  
to becoming trustees and in some cases paid workers.  
That's a long slow process that takes years, and years, and years.**

”

Midlands DPO

## Limited Capacity to Reach out to Younger Disabled People

Local and regional capacity to specifically build intergenerational links between young Disabled people and older Disabled people, and to bring on the next generation of leaders in our movement, was cited as a key need by DPOs. Developing work with young Disabled people requires dedicated resources and skills in youth engagement and movement building. There are only a handful of DPOs that have developed effective work to recruit the next generation of leaders. These include Greater Manchester Coalition of Disabled People, Equal Lives, Darlington Association on Disability and the Alliance for Inclusive Education (ALLFIE).

Other DPOs are trying to attract younger members:

**Let's learn  
from  
each other!**



“

It's almost a whole generation that have come from the disability rights movement who are now retiring or sadly passing away, and what we are trying to do is engage with a younger sector of Disabled people; our user engagement is doing a lot around this. What do young people want from us as an organisation and what do we need to do so that you come work for us – we are trying to become attractive and relevant to young people

South West DPO

”

“

We are working with a youth group of women and girls with learning difficulties. Issue with skills – especially office skills. Lot of Disabled women have missed out in education and don't have the written skills.

”

Women's DPO London

And are trying to get young Disabled people into their governance structures:

“

We also have a shadow-board now, which is young people we're hoping to learn to act as a board and eventually join us. I think this is a key prong, but you need a governance structure where there's something to fit into. You can do a load of work to get people geed up, but there isn't a place where they fit into governance and have a way to say anything.

”

South West DPO

This was a key and common priority issue for DPOs:

“

The challenge is how far the ideas behind the social model have slipped away, and for younger Disabled people it's not at the current scene for them – not relevant. How do you make the social model more relevant?

”

South West DPO

There is a lack of dedicated resources and skills in DPOs to carry out specific youth engagement and movement building. There are also limited opportunities for younger Disabled people to develop a social model of disability understanding of their lived experience or to understand their rights and how to take collective action:

“

What we found is there is a big gap, the older generation were dying off or leaving and there was a big gap where younger people may not be identifying as part of the disability rights movement as well as just trying to get them engaged and a bit riled up.

We find it very difficult to recruit young Disabled people to work for a disability rights organisation or one that seen to be involved with the movement because they don't necessarily associate with being part of that movement and there's a big issue around identification of younger people as disabled people. They seem to shy away from calling themselves a disabled person and see it as a negative association to have.

”

South West DPO



There is an urgent need to overcome the effects of the medical model of disability, segregated education, stigma, internalised oppression and embedded self-esteem issues for young Disabled people.

## Covid-19 Disabled People and DPOs

Austerity and Covid -19 have both impacted on DPOs. They have increased and altered the needs of their service users:

“

demand is massive and we can hardly begin to scratch the surfaces.

Midlands DPO

”

The nature of rising demand and complexity of demand is putting greater strain on DPOs:

“

...two or three times a week, somebody will call and be crying in distress saying “when can we come back?”, “when can we see you?”. “we miss you”, “when can we come in?”

North Yorkshire DPO

”

“

the turn-around for these issues are longer, they cannot sufficiently be dealt with in a single phone call.

South East DPO

”

Digital exclusion was highlighted as a growing issue of concern. It was recognised that many more people are becoming digital, but there are still many Disabled people and their families who remained excluded from digital resources and the internet:

“

Have adapted services to be delivered virtually, but older service users cannot access this. We have received funding for tech befriending service which should hopefully resolve this.

Midlands DPO

”

The increase in people doing things online was noted as having both positive and negative effects. There were some general concerns about the switch to digital provision becoming the default and not being developed with Disabled people's needs/ preferences in mind:

“

On the positive side, it was noted that increasing use of the internet as having enabled some people to access services and support (including medical, care, support, benefit advice, shopping) or connect with others, including family, friends and neighbours.

On the negative, there was concern that it had broadened the digital divide – with some (older) people not interested in or unable to use digital provision – and other (younger) people embracing digital provision to the exclusion of other means of connectedness.

”

South West DPO

Generally, DPOs have experienced a significant increase in demand as a result of Covid-19. In many cases DPOs became the front line provider of statutory /critical services. Here is a list of Covid-19 services provided by one DPO in the South West:

- Providing regular welfare checks on behalf of Local Authorities to over 1,000 Disabled people, who receive Direct Payments, including risk assessing their care package provision
- Arranging and certifying vaccination for thousands of people providing personal care to Disabled people
- Arranging emergency care for those whose vital care provision has been disrupted by the pandemic
- Distributing PPE to personal assistants employed directly by Disabled people (as opposed to care provider agencies) across the region
- Delivering vital supplies, including medication and food across the region
- Developing new digital peer-support networks for isolated Disabled people
- Campaigning against the removal of Disabled people's human rights under the Coronavirus Act



For many Disabled people Covid-19 increased their experience of isolation especially if they were in residential settings with people being refused visits by family members and Disabled people not able to access support from PAs /support workers:

“

We campaign for the right for all to have enough support; including, recently, the right to take a PA into hospital with you despite ambiguous hospital guidance.

South West DPO

”

The reduction of the right to day-to-day living, financial exclusion and hardship was highlighted as an area of high concern, this having been exacerbated by Covid-19. Concerns were raised about many Disabled people experiencing high fuel bills and other increased costs, with a concurrent reduced ability to seek and gain social care, advice, support or advocacy and lack of access to food delivery service - leaving many moving into (problematic) debt.

### Impact on DPOs:

The impact of Covid-19 has included LAs/funders cancelling on-going and planned work with DPOs. There is concern that relationships are unlikely to return to the previous way of doing things, leaving DPOs isolated and Disabled people's voices not being heard.

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There has been a slide from user led organisations to non-user led organisations – using the pandemic as an excuse to bypass user led groups.

There is a great fear for post-Covid society of Disabled People being institutionalised, and the Care Act being ignored.

I think that it is time for Disabled People to get their courage /anger back and say it how it is. Disabled People were categorised as vulnerable during pandemic, yet equality has been rolled back and care packages cut.

The public need to be made aware of this – and we owe it to the next generation.

South East DPO

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## Section 3 - Meeting the infrastructure, voice and policy needs of DPOs

The recommendations in this final section of the report have come from meetings and co-production workshops with the 8 Regional DPO partners who have carried out the research.

### Overview: A new vision for DPOs

Our vision is to reclaim our power as DPOs and as a Disabled people's rights movement and to get our equality and inclusion back on track by building an independent, sustainable, powerful infrastructure network of regional DPOs that:

- provides effective infrastructure support so DPOs can lead the change needed in their local communities and deliver day to day support that is crucial to Disabled people being able to access rights, entitlements, opportunities, choice and control
- engages with decision makers as respected and valued partners, who together can develop solutions to the most urgent domestic challenges of 21 century including: inequality & exclusion and social care/independent living support, building on the best of our movement's track record of innovative policy and practice
- will learn from, and build alliances with, other social justice movements and develop new ways of working so we have a sector that is genuinely intersectional, intergenerational and centers the most marginalized groups of Disabled people.
- empowers, upskills and equips our organisations and communities, bringing young Disabled people into the movement, developing the next generation of Disabled leaders and supporting our current leaders.
- creates change in our wider communities and in local, regional and national decision and policy making structures and gathers robust evidence about the added value and impact of our sector as user-led organisations so we can strengthen our capacity to shift the power balance and re-set our relationships with those with power





We want and need to create a society where it is unthinkable that a policy or decision about Disabled people would be made without the involvement of Disabled people and our organisations. We want DPOs to be viewed as ‘must have / go to’ partners, critical friends and co-producers in any work involving equality, community, wellbeing and social justice. We want the social model of disability, the principles and practice of intersectionality, co-production and the embedding of a human rights approach to disability to be embedded in the work of all public bodies.

# **What organisational and infrastructure capacity building support does the DPO sector need at a regional and national level?**

## **Regional level recommendations:**

There are some previous and current examples of regional infrastructure support provided by DPOs that need to be built on and expanded to include the following range of key organisational and infrastructure capacity building support functions across the 8 regions:

- regional co-ordination and facilitation to set up and run accessible DPO peer networks for local DPOs, where staff and Trustees can meet to share and receive information, take part in training, share support, top tips and insights and counter growing isolation and fragmentation.
- develop and deliver packages of training and 121 support to DPOs on business and organisational issues including: strategic planning, costing and modelling services, funding and income generation, HR policies and practice and measuring and evaluating impact
- provide support to incubate and pilot innovations and new approaches including co-production /user design and HR support, for example developing best practice training and resources for supporting neuro-divergent staff and staff experiencing mental distress.
- develop and deliver training and support to current DPO leaders including setting up CEO networks, creating regional mentoring and work coach opportunities, subsidised entry to professional qualifications.
- research, develop and pilot ways of increasing the recruitment of Disabled people to our sector including funding traineeships, regional secondments, creating better terms and conditions.
- specific resources and capacity to help set up DPOs in localities where there is no functioning DPO.

- research and develop ways of developing and supporting Disabled Trustees and user-led models of governance including work with the Charity Commission, NCVO and development of specific DPO Trustee governance training and recruitment support.
- providing regional Trustee support including help with recruitment, induction, training and on-going support.
- provide strategic high quality social media coms, coordinated at a regional level, to increase our presence and profile in the media
- regional promotion and evidencing of the added value DPOs bring to communities, Disabled people's inclusion and social justice work and service delivery.
- regional representation and strategic relationship building with key statutory bodies and funders.

## **National level recommendations:**

There is a need for a coordinated national infrastructure support function for DPOs to carry out work that cannot be done at a regional level including:

- national relationship building with national funders, policy makers, 'think-tanks', equalities infrastructure organisations and capacity building organisations like NCVO
- capacity to develop and pilot bespoke training packages including HR training and support to help DPOs manage complex impairment and access needs
- capacity to develop and pilot resources and tools to support DPOs to capture and demonstrate their added-value
- capacity to develop bespoke accessible business and organisational tools including impact measurement, co-production and user design
- capacity to develop bespoke professional qualification opportunities and wider leadership development and support solutions
- capacity to research, develop and pilot new ways of working, for example utilising video conferencing platforms in DPO work that if effective can be rolled out across regions

## What movement building support does the DPO sector need at a regional and national level?

### Regional level recommendations:

There is an urgent need for long term support and core funding to meet following needs:

- regional long-term capacity to build intergenerational links between young Disabled people and older Disabled people to empower young Disabled people and to support them to become the next generation of leaders in our sector and movement.
- regional capacity to set up and carry out specific long-term empowerment and rights based work with younger Disabled people
- regional capacity to support and develop our movement's intersectional skills and practice so DPOs can become more inclusive, anti-discriminatory and better reflect marginalized groups of Disabled people
- set up and provide dedicated long-term funding and support to intersectional BAME, LGBTQI and women's DPOs in each region
- regional capacity to deliver disability equality and rights training to local DPOs who in turn are resourced to deliver this training to their Disabled communities
- dedicated resources at a regional and local DPOs level to enable DPOs to reach out and connect with marginalised Disabled people including Disabled people in institutions
- regional partnership working and alliance building with wider equality movements

## National level recommendations:

There is a need for a coordinated national infrastructure support function for DPOs to carry out work that cannot be done at a regional level including:

- co-ordination and support to bring DPOs together at a national level to create opportunities for sharing, reflection and developing our movements thinking, practice inclusiveness and innovation
- co-ordinate and support intersectional work at a national level
- national capacity to support and co-ordinate BAME, LGBTQI and women's DPOs in each region to work at a national level
- national partnership working and alliance building with wider equality movements



# What voice, policy and representation support does the DPO sector need at a regional and national level?

## Regional level recommendations:

DPOs across the 8 regions of England need funding to carry out a range of voice, policy and representation work including:

- setting up and supporting regional DPO networks that bring local DPOs together to develop a collective voice on regional need and policy issues
- carrying out regional peer research to build a stronger regional evidence base on disability equality issues and needs of local Disabled people and communities
- facilitating and brokering relationships at a regional level between decision-makers / those with power and DPOs
- carrying out regional influencing and relationship building work including meetings with regional statutory bodies like NHS, LAs, DWP, wider third sector and private sector organisations
- providing training and support to DPOs on strategic communication, marketing and influencing skills/approaches

## National level recommendations:

Our sector needs capacity and resources to co-ordinate regional DPOs to carry out the following national functions:

- setting up, supporting and co-ordinating DPO representation on national bodies to develop a national, collective voice on need and policy issues
- carrying out national peer research to build a stronger national evidence base on disability equality issues and needs of Disabled people and communities across England

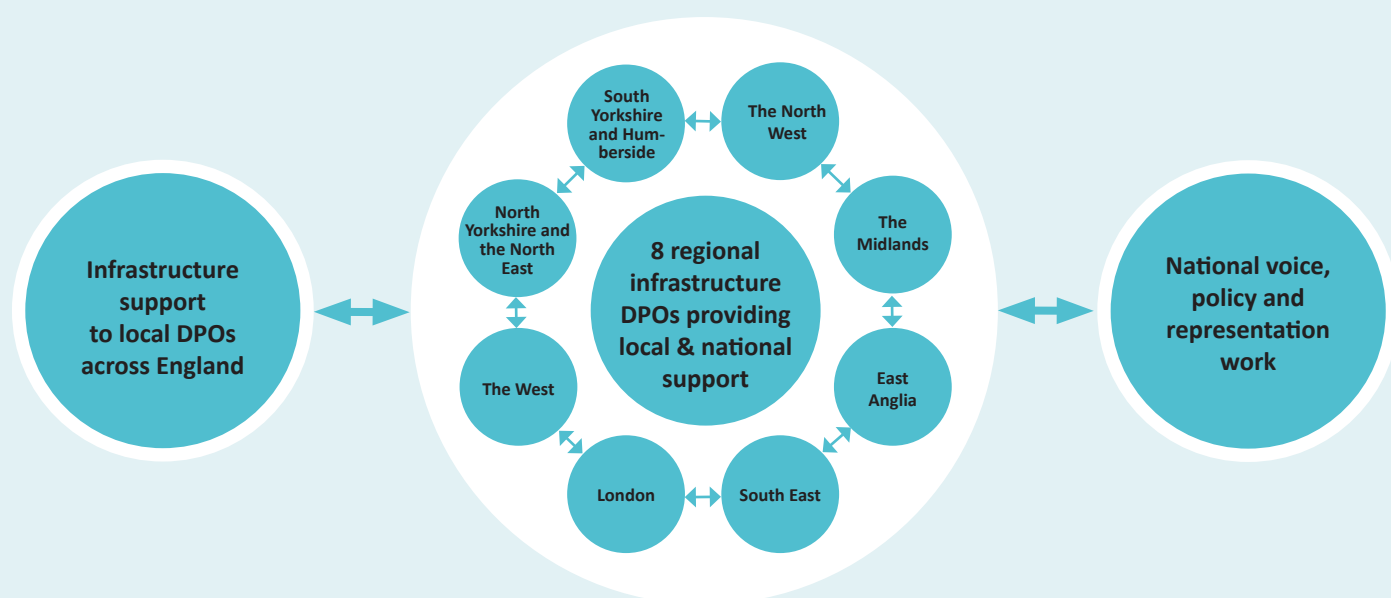
- carrying out national influencing and relationship building work for example meetings with statutory bodies like UK government, Charity Commission.
- carrying out coalition and partnership building work with other human rights / equalities movements and organisations to amplify voices, develop cross cutting policy and build stronger movements of change
- providing strategic communications support to ensure a strong national media profile



## What could regional and national DPO infrastructure look like? Some initial ideas

We strongly recommend infrastructure support is focused on building and strengthening the role and capacity of regional DPOs in each of the 8 regions of England. A well resourced and co-ordinated group of DPOs providing regional infrastructure support is the most effective way of supporting local DPOs in each region to thrive . Supporting and co-ordinating regional DPOs to carry out national functions is also the most effective way of carrying out national work that reflects the needs of grassroots DPOs and eliminates the cost and bureaucracy of creating a national DPO that sits above local and regional DPOs.

### Recommended form for DPO infrastructure







## Principles and values:

All infrastructure must:

- reflect a rights-based, social model of disability and intersectional approach.
- be run by and for Disabled people and meet DPO definition criteria
- Pan-impairment, diverse, inter-sectional and inclusive.
- Bottom-up and grassroots –starting with, and centering, the needs, issues, concerns and aspirations of Disabled people.
- Build the grassroots – creating the conditions for strong local DPOs through empowering regional and national infrastructure.
- Devolve work to regional partners where possible, with regional working together in a co-ordinated way to carry out national work. National work is delivered by co-ordinating and supporting regional DPOs to play a national role.
- Fund and support long term specific intersectional DPO organisations at a regional and national level.

We estimate between 8-10 years of funding at between £10-18 million is needed to deliver the full range of recommendations detailed above across England. This is a very significant amount of money but we strongly believe we cannot as a society afford not to make this investment in tackling the deep and persistent structural inequality, marginalisation and discrimination that is blighting the lives, and the futures, of so many millions of Disabled people.



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improving lives of disabled people for over 25 years.

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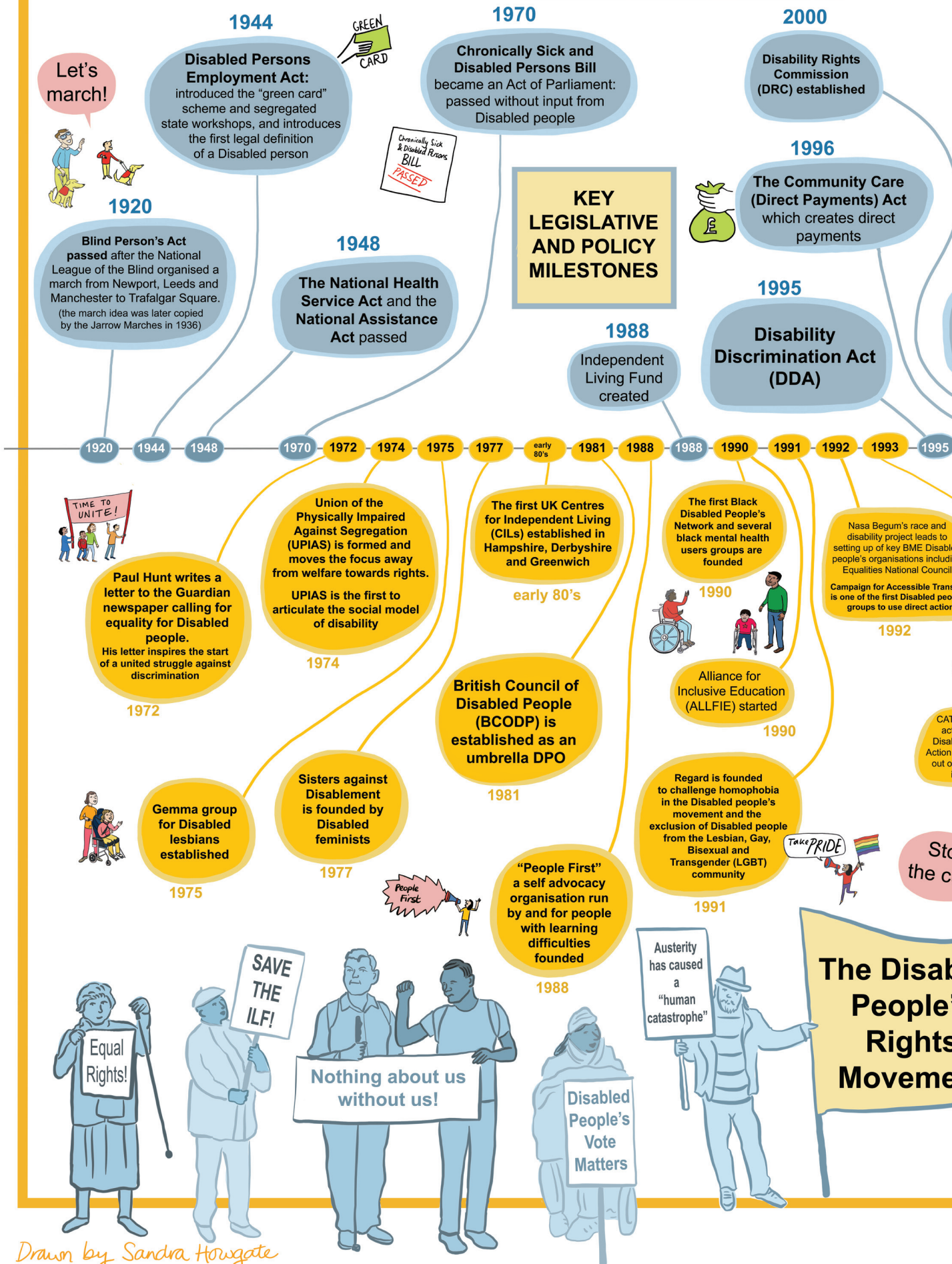


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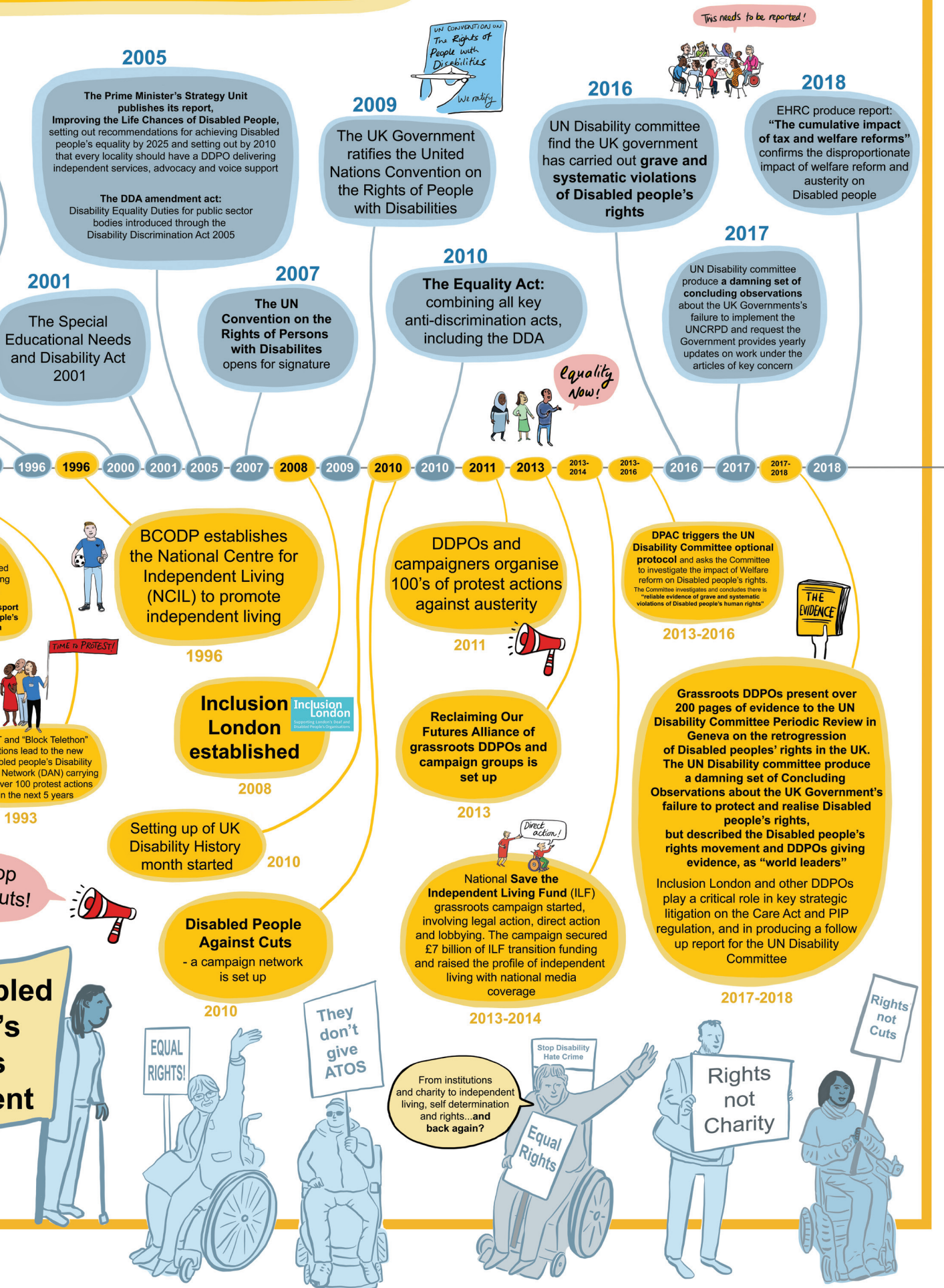
# Timeline of the Disabled People's Movement



Drawn by Sandra Hougate



# Rights Movement in the UK





Inclusion London promotes equality and inclusion for Deaf and Disabled people by supporting the development of Deaf and Disabled People's Organisations (DDPOs) across London.

[www.inclusionlondon.org.uk](http://www.inclusionlondon.org.uk)

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Most of the illustrations in this document have been drawn by Sarah Howgate.

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