

2024

**FUNDING
JUSTICE
FOR DPOS**

A POSITION STATEMENT

table of CONTENTS

- One. Introduction. 4
 - i. Who we are. 4
 - ii. Why this position statement? 5
- Two. Background..... 5
 - ii. DPOs and ‘By-And-For’ organisations compared to non-Disabled people-led charities. 6
 - iii. The legal framework for this statement. 8
 - iv. What we demand..... 9
- Three. What’s Gone Wrong? 10
 - i. Limited availability of dedicated DPO funding programmes. 10
 - ii. Lack of understanding and engagement..... 10
 - iii. Administrative burdens. 11
 - iv. Bias against our community and movement..... 12
 - v. Structural Issues in Funding Schemes. 12
- Four. A call to Action: our Demands for Funding Justice. 14

1) Commit to funding self-representation. 14

2) Commit to Justice and Equitable Power Re-distribution..... 15

3) Break the bureaucracy and enhance Accessibility. 15

4) Recognise our movement!..... 15

What next? 16

Five. Questions for grant-making trusts/ funders to consider..... 17

One. Introduction.

i. Who we are.

We are a coalition of Disabled People's Organisations¹ (DPOs) and grassroots groups led By and For Disabled people². We are founded on the principles of the Social Model of Disability³ and Disability Justice⁴.

We aim to dismantle systemic and institutional barriers and advocate for the rights and inclusion of Disabled people in all aspects of society.

¹ **Disabled Peoples Organisations:** An umbrella term for an organisation or group where Disabled people represent at least 75% of the board and 50% of staff and volunteers. DPOs actively demonstrate a commitment to the Social Model of Disability through its work, values and operations. Under the umbrella of DPO are D/deaf and Disabled People's Organisations (DDPOs), User-led Organisations (ULOs), Disabled-People Led Groups and Intersectional DPOs. An in-depth description of DPOs and By and For Organisations can be found in our Analysis '[We, Disabled People](#)'.

² **Disabled people:** We use the Social Model of disability to define Disabled people, which says that people are disabled by barriers in society. In this report, Disabled people can include: people with physical impairment, visual impairment, Blind, D/deaf people and people with hearing loss, long-term health conditions, invisible impairment, people with learning difficulties, people who experience mental distress and people who are neuro-divergent.

We acknowledge the diversity of language preferences across our community and have strived to make space for different self-identifications. We recognise that terminology is a continual debate across our movement, and we ask readers to keep in mind that this document focuses on funding injustice against our self-led work.

³ **The Social Model of Disability** emphasises that disability is not an inherent trait of an individual, but a result of barriers and discrimination imposed by society because a person's mind and body function differently from what is considered normative. *An in-depth description of the Social Model of Disability can be found in our Analysis 'The Tragedy Model versus the Social Model of Disability'.*

⁴ **Disability Justice:** A framework and movement that goes beyond the traditional civil rights-based approach to disability. It recognises the intersecting identities and experiences of D/deaf and Disabled people and focuses on collective liberation, interdependence, and the dismantling of all forms of systemic oppression (Sans Invalid, 2019).

ii. Why this position statement?

As organisations Led By and For Disabled people, we have come together to demand funding justice for our sector.

Despite our 45-year track record in advancing disability rights and systemic change, we face substantial challenges in securing necessary resources. The current funding landscape is structurally inequitable, inaccessible and fails to recognise the unique contributions and needs of DPOs.

This position statement is a call for change: we must address the disparities we describe in this statement to ensure that funding practices align with the principles of justice and equity so that DPOs have the resources we need to make the world a better place.

Two. Background.

i. What are DPOs and By-And-For Organisations?

While there is no universally accepted definition or standard for a DPO, this coalition and the DPO Forum England recognise an organisation or group as a DPO when Disabled people represent at least 75% of the board and 50% of staff and volunteers. Additionally, a DPO actively

demonstrates its commitment to the Social Model of Disability through its work, values and operations.

Representing the community we work with and for makes DPOs a type of **"by and for" organisation**. A "by and for" organisation is both led by members of the community it serves and operates primarily for that community's collective benefit. It ensures that the voices and needs of its own community are at the forefront of advocacy and initiatives.

ii. DPOs and 'By-And-For' organisations compared to non-Disabled people-led charities.

By developing our own organisations to represent our voices, DPOs provide an authentic space to campaign for our rights, equity and justice. DPOs are not just stakeholders but the legitimate voices of Disabled people, ensuring that our lived experiences inform the creation of laws, policies, and practices designed to remove disabling barriers.

DPOs have been vital in advancing Disabled people's equality globally. Since the 1980s, our organisations have coproduced theory and practice that has transformed our lives; including creating the Social Model of Disability, the

UNCRPD⁵, the practice of independent living⁶ and self-directed support—our organisations to work to remove disabling barriers and advance rights and equity⁷.

Disabled people still experience systemic exclusion and discrimination across all areas of life and are marginalised by institutions discussing **our** rights **without** us. Disability Charities or Non-Disabled People Led Organisations are organisations that focus on disability but are not led by Disabled people.

Non-Disabled People Led Organisations are actively harmful to DPOs and the Disabled people's movement. They appropriate our language about empowerment yet do not share their access to decision-makers or people in power with us. They take up the majority of funding⁸ going into the disability space whilst not letting Disabled people lead their organisations, campaigns and policy work. This perpetuates the paternalistic and charitable marginalisation of Disabled people. In the context of a professionalised sector, organisations not led by Disabled people *financially* benefit from talking about our oppression in the same society in which they are *privileged* by it.

⁵ **UNCRPD:** United Nations Convention on the Rights of Disabled Persons.

⁶ **Independent Living:** The right to live independently and to be included in the community. As declared in Article 19 of the UN CRPD states that parties are required to ensure that Disabled people “Have the opportunity to choose their place of residence of where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement”.

⁷ **Disability Equity:** Disability Equity combines The Social Model and Disability Justice; advocating that equality alone does not provide for the additional support that will remove disabling barriers and create justice.

⁸ We *highly* recommend that the reader review our analysis, [‘What are Non-Representative Organisations?’](#) which breaks down the funding disparity between DPOs and non-disabled people-led organisations.

iii. The legal framework for this statement.

This position statement is informed by forty years of expertise and the mandate of the UNCRPD.

Under Article 4.3 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), governments⁹ must closely consult with and actively involve Disabled people through our '*representative organisations*' in decision-making processes. This reinforces our movement's principle of "Nothing About Us Without Us": decisions affecting Disabled people must not be made without the direct participation of Disabled people.

By sidelining DPOs, governments and funding organisations violate the spirit of the UNCRPD and undermine the fundamental rights of Disabled people to self-representation and self-determination.

⁹ The United Kingdom ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2009. Therefore, the UK is a 'party to', or agreed to uphold, the United UN CRPD regulations. The UK is held to account for its implementation of the convention by The UN Committee on the CRPD.

iv. What we demand.

We demand an equitable distribution of funding to our communities and complete divestment¹⁰ from organisations led by non-Disabled people who claim to speak for us.

Funding programmes that aim to tackle the structural discrimination and social injustice of Disabled people should be directed to DPOs and organisations and groups Led By and For Disabled people; ensuring that the resources are used effectively to promote real, lasting change.

All organisations and agencies that distribute resources for social justice should evaluate the history of marginalising led by and for organisations and, in light of this, implement reparations for systemic harm.

This involves changing the structure your organisation, reevaluate how to distribute resources and deviate from organisations and partners that perpetuate harm.

¹⁰ **Divestment:** The process of withdrawing financial support from organisations or sectors that are deemed harmful or unethical and redirecting those funds towards more ethical, equitable and effective alternatives.

It is unacceptable to support non-disabled people to speak for us and claim that they know what's better for us than we do. Funders would not dream of funding cis men to speak for women, trans people, and gender-marginalised people; It's imperative to rally behind disabled people and support disability justice movements with the same vigour and dedication as other social justice causes.

Three. What's Gone Wrong?

In this section, we'll break down how the funding landscape is structurally inequitable, inaccessible and marginalises DPOs.

i. Limited availability of dedicated DPO funding programmes.

- There is a limited availability of funding programmes that DPOs can apply to.
- To our knowledge, only two funded programmes dedicated to DPOs currently exist: the [Lloyds Bank Foundation DDPO programme](#) and [Trust for London's Funding for Disability Justice](#).

ii. Lack of understanding and engagement.

- Funding organisations often do not understand the difference between DPOs, Led By and For organisations and disability charities, nor the Social Model of Disability¹¹.
- Funding organisations often lack a comprehensive understanding of DPOs and Disability Justice and how disablism is another structural form of injustice and oppression.

¹¹ An in-depth description of the difference between DPOs, Led By and For organisations and disability charities can be found in our Analysis '[We, Disabled People](#)'.

A description of the Social Model of Disability can be found in our Analysis '[The Tragedy Model versus the Social Model of Disability](#)'.

- Funding organisations do not routinely require, capture or review data on whether the disability-focused organisations they fund are run By and For Disabled people or not; resulting in DPO's marginalisation.
- BSL-led grants are not fairly distributed, and they do not prioritise D/deaf-led work or foster relationships with local DPOs.
- Systemically, disability charities that are led by non-Disabled people have been disproportionately privileged in the funding landscape, taking the majority of disability related funding.
- Charities led by non-Disabled people often ignore the existence of DPOs, considering us only when they wish to exploit our lived experience, contacts and expert knowledge.
 - Disability Charities have a history of exploiting Disabled people, control of resources, & co-optation of disability rights. To learn more, we highly recommend that Funders review our Analysis ['What are Non-Representative Organisations?'](#).

iii. Administrative burdens.

- Application processes remain inaccessible.
- Short application deadlines disadvantage organisations without professional bid writers.
- Funding applications require unnecessary information, creating excessive administrative burdens.
- Application processes and grant design often ignore the additional administrative needs of DPOs, making timescales disproportionately difficult.

- Bureaucratic evaluation feedback is required instead of accessible, equitable processes.

iv. Bias against our community and movement.

- There is a systemic lack of awareness about the importance of DPOs and the Disability Justice movement.
- Funding preferences often favour vertical programs and medical model-based services over systemic change, civil and human rights and movement organising.
- Large charities led by non-Disabled people often amass resources and unrestricted funding while neglecting to include or centre Disabled people in their decision-making processes - whether as staff, leadership or on trustee boards.

v. Structural Issues in Funding Schemes.

- Typical grant-giving models (e.g., three-year service-based programmes) do not support long-term systemic work.
- Limited funding restricts the capacity for structural change and perpetuates cycles of inequity.
- Funders have a limited understanding of how led By and For organisations bring about system change and therefore tend to privilege organisations which are strong on service delivery / managerial approaches rather than grassroots activism and social change.

- Grant-making trusts don't tend to recognise or provide additional funding for access / communication / support costs that can make DPO work more expensive; disproportionately eliminating DPOs from the shortlisting process.
- Funding-making trusts often require quantitative evaluation and monitoring reports instead of more qualitative, proactive engagement.
- Grants don't tend consider the access costs for independent Disabled / D/deaf evaluators, that can make DPO's evaluation more expensive.
- Lack of appropriate 'Funder Plus'¹² and capacity-building support, delivered by Disabled people with the social model and DPO knowledge needed to support our sector.

¹² **Funder Plus** is a term that describes a range of activities that are in addition to a grant or the grant-making process. It can also be referred to as "grants plus". Funder Plus programs are designed to help funded organisations improve their capacity, resilience, and sustainability.

Four. A call to Action: our Demands for Funding Justice.

In this section, we'll break down four steps to address the disparities described in section [Three.](#), and change the funding landscape to support disability justice.

We have drafted some additional details, which can be found in our Analysis [‘What do our asks look like in practice’](#).

1) Commit to funding self-representation.

- a) Create Dedicated Long-Term Core Funding Programmes for the DPO sector.
- b) Meet our full access, support and inclusion costs.
- c) Equitably distribute funds to Intersectional¹³, PwLDs¹⁴, BSL-Led, D/deaf-Led and D/deafblind-led organisations and groups.
- d) Fund Intersectional Work.
- e) Divest¹⁵ disability related resources from organisations led by non-Disabled people and organisations that create harm.
- f) Ensure representation in your Grantee Capacity Building.

¹³ **Intersectional Led By-And-For groups:** A community organisation governed and operated by people from the intersectionally marginalised communities it serves (e.g., Deaf migrants).

¹⁴ Persons With Learning Difficulties or Disabilities.

¹⁵ For an in-depth explanation, please read our analysis [‘Divestment and the Injustice of Misrepresentation’](#).

2) Commit to Justice and Equitable Power Re-distribution.

- a) Shift priorities towards long-term systemic change.
- b) Shift Decision-making power from a funding board to grassroots communities.
- c) Include Disabled people with intersectional experiences at every level.
- d) Develop a comprehensive understanding of our sector.

3) Break the bureaucracy and enhance Accessibility.

- a) Design end to end, accessible programmes, based on Disability Justice principles and the Social Model of Disability.
- b) Create reasonable application deadlines.
- c) Provide equitable evaluation processes.
- d) Free the ownership of data about our communities.
- e) Design end to end, accessible applications.

4) Recognise our movement!

- a) Develop a comprehensive understanding of Disability Justice and our movement at all levels of your organisation.
- b) Hire Disabled people as expert consultants to train and evaluate your internalised ableism/structural oppression.

c) Divest all resources from all organisations that mirror the charitable and medical models of disability.

What next?

We believe in the power of coproduction and know that changing the funding landscape cannot be done alone. We want to coproduce a strategy for change with you!

If you would like to join us on our journey, please contact us. Details can be found on our campaign page: <https://www.disabilityrightsuk.org/funding-justice>.

Five. Questions for grant-making trusts/ funders to consider.

1) How many DPOs versus disability charities led by non-Disabled people does your organisation fund?

Can you answer these questions?

- a) Does the organisation you fund's board have at least 75% Disabled and D/deaf trustees? Yes / No
- b) Does their workforce consist of at least 51% Disabled and D/deaf employees? Yes / No
- c) Are at least 51% of their volunteering team Disabled and D/deaf? Yes / No
- d) Does the organisation have user involvement forums? Yes / No

2) When did you last look at the power distribution in your organisation?

For example:

- a) What percentage of your Board of Trustees and senior leadership identify as Disabled and D/deaf?
- b) What economic communities do your Board of Trustees come from?

c) How many of your Board of Trustees have intersecting marginalised identities? Some examples: Disabled, Racialised and ethnically minoritised, LGBTQIA 2S+, gender marginalised, migrant and refugee, working class, Roma and traveller.

3) Have your staff team and board received Disability Equity or Disability Justice training?

4) Do you involve Disabled and D/deaf people in your decision-making process concerning what social issues require funding from the design phase of the programme?

5) How do you include disability in all your social justice/equality work?

6) Will you join a national group of funders to co-produce a funding justice plan with us?

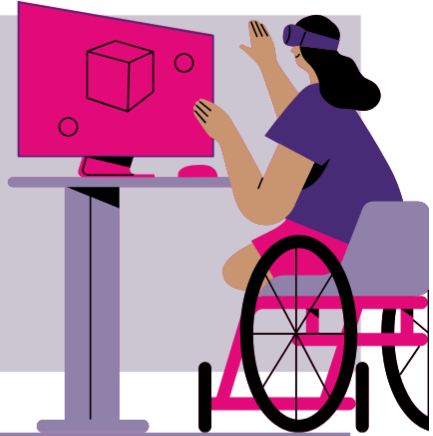
FOUR

FUNDING JUSTICE 4 DPOS

STEPS TO FUNDING JUSTICE

1

FUND SELF-
REPRESENTATION



2

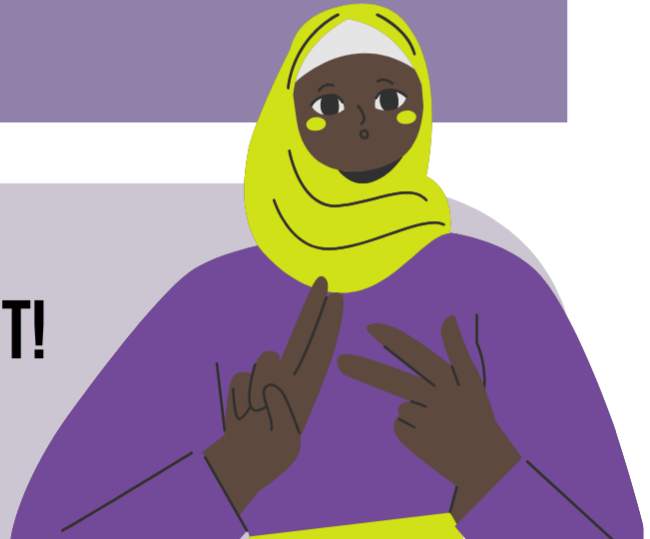
DISTRIBUTE
POWER
EQUITABLY

3

BREAK THE
BUREAUCRACY,
ENHANCE
ACCESSIBILITY

4

RECOGNISE OUR MOVEMENT!



JOIN THE MOVEMENT!

THE TIME TO GIVE POWER BACK TO THE COMMUNITY IS NOW

