

# Executive Summary



Disability

**Listen Include Build**

## Introduction

The purpose of this report is to examine some of the major challenges and opportunities facing Disabled People's Organisations (DPOs) at the beginning of the 21st century.

DPOs are run and controlled by disabled people and evolved during the course of the 20th century from a few organisations focusing mainly on disabled people's welfare and employment to myriad organisations focused on achieving equality and civil rights.

This paper is written in the context of a successful £4.25m bid that a number of Disabled People's Organisations and their allies, collectively named the Disability LIB alliance, submitted to the Big Lottery Fund to build the capacity of DPOs. It aims to explore the changing role of DPOs, assess their strengths and weaknesses and suggest a range of ways to ensure DPOs continue to represent the voices of disabled people across the UK in an effective and sustainable way.

The Disability LIB alliance consists of the Alliance for Inclusive Education, Disability Awareness in Action, Equalities National Council, People First, Preston DISC, Scope and the UK Disabled People's Council.

## Chapter 1 -

### What are Disabled People's Organisations and why do they matter?

#### Defining Disabled People's Organisations

Defining DPOs is not a simple task. Although they fall into the wider category of user-led organisations, their role is not identical to that of other user-led groups. Crucially, DPOs are defined by the fact that they are run and controlled by disabled people themselves, that they subscribe to the social model of disability and have an implicit or explicit commitment to the human rights of disabled people. Of the 200 DPOs that the Disability LIB alliance has contacted, most are pan-impairment. Of those DPOs which work with a specific groups of disabled people, such as People First, mental health system user groups and some Black and minority ethnic (BME) focused groups, they do not define people according to their medical label.

#### The role of Disabled People's Organisations

DPOs were created by disabled people as a vehicle to challenge the conscious and systematic exclusion of disabled people from mainstream life. The first DPOs were established in the late 1800s, but it was not until the 1980s in the UK that modern DPOs really became established and widespread.

During the 1970s and 1980s DPOs key ideological concepts like the Social Model of Disability and Independent Living were defined and refined as disabled people deconstructed the whole foundation of political and social attitudes towards disability and impairment.<sup>1</sup> The phrase ‘nothing about us without us’ was coined to articulate the Disabled People’s Movements core values and DPOs united in the struggle to achieve civil rights and legal protection from discrimination.

With basic rights secured in law<sup>2</sup>, the role of the Disabled People’s Movement and Disabled People’s Organisations is now less clear-cut than 20 years ago. Many DPOs set up in the ’80s and ’90s are struggling to identify where they should focus their resources and attention in a political and economic landscape that is changing rapidly.

### **Disabled People’s Organisations and Disability Charities**

The modern Disabled People’s Movement and their organisations developed in part as a reaction to charities ‘for’ disabled people, which provided ‘services’, such as special schools, hospitals and institutions, that segregated disabled people from mainstream society. DPOs questioned the legitimacy of disability charities, which did not involve disabled people

in decisions about their lives or futures, and raised money by portraying disabled people as passive sufferers in need of charity and pity.

DPOs challenged government policies that refused to recognise disabled people’s entitlement to equal citizenship, and their support for organisations that oppressed disabled people while claiming to help them. The impasse between DPOs and disability charities proved difficult to overcome until 2004 when Scope and a number of DPOs published a statement of collaboration on the Human and Civil Rights of Disabled People in the foreword to *Disablism: How to tackle the last prejudice*.<sup>3</sup>

This marked the start of a new era of co-operation and mutual understanding between historical enemies for the benefit of both. Crucial to this is Scope’s explicit undertaking to become an ally of the Disabled People’s Movement and individual disabled people. This new way of working is still in its infancy and has yet to be embraced by all disability charities and DPOs. But the journey from enemy to ally is a vital one if the considerable resources and passion of the disability sector are to be used to greatest effect.

<sup>1</sup> Oliver M. (1984) *The Politics of Disability Critical Social Policy* Vol. 11 pp 21-32.

<sup>2</sup> See Disability Discrimination Acts 1995 and 2005, Human Rights Act 1998, the Prime Minister’s Strategy Unit’s *Improving the Life Chances of Disabled People* report and recommendations and the UN Convention on the Rights of Persons with Disabilities, 2007.

<sup>3</sup> Miller P and Parker S (2004) *Disablism: How to tackle the last prejudice* London: Demos.

## Chapter 2 -

### Disabled People's Organisations in the UK today

This chapter looks in more depth at what DPOs do and how they are structured. It also looks at the key challenges they face in achieving their aim of becoming an effective, sustainable and vocal champion of disabled people's rights across the UK and internationally. Much of this chapter draws on research conducted as part of Stage 1 of the Disability LIB alliance bid and focuses on the experiences of partner organisations and the organisations they work with.

#### What DPOs do

The DPOs surveyed by the Disability LIB partners covered a wide range of activities between them. These can be divided into three broad categories:

- Influencing
- Providing Services
- Peer Support

#### Types of DPOs

The DPOs surveyed by the Disability LIB alliance partners included large Centres for Independent Living or regional or sub-regional 'umbrella' groups; local, regional and national organisations representing 'communities of interest'; service provider organisations; smaller and medium size single-issue groups (focusing on access,

leisure, arts and so on) and, at a local level, some single impairment groups.

#### The political climate

The wider political climate appears, on the surface, to be favourable to DPOs. There is an unprecedented focus on user-involvement in service planning and delivery, particularly, but not only, around health and social care.

However, despite the favourable environment, DPOs are in trouble. The research conducted by Disability LIB partners has revealed a sector in crisis.

### Key challenges facing Disabled People's Organisations

#### Sustainable funding

The Disability LIB partners' mapping exercise showed that across the country, many DPOs have closed due to lack of sustainable funding. Barriers to winning contracts or fundings bids include a lack of fundraising and business planning expertise, inaccessible application procedures and bureaucracy, reluctance to use disempowering charity 'tin-shaking' fundraising methods, a lack of medium- and long-term service contracts which results in considerable financial and staff insecurity, and increased competition from the private sector and larger disability charities.

### **The extra cost of being a DPO**

DPOs often face substantial, additional costs because their staff or volunteers are disabled people or because they work with disabled people. These extra costs are rarely recognised by funders or commissioners. These extra costs are also a factor in starting up new DPOs and are a key factor in the numbers of small organisations that fold within their first year.

### **Commissioning and competitive tendering**

Local and health authorities are gradually replacing service level agreements with a more complex commissioning process, and tendering for contracts. The contract culture is a challenge to all voluntary sector organisations, but particularly to smaller user-led organisations who often don't have the experience or resources to compete with much larger providers.

Cost-effectiveness criteria also do not take account of the 'added-value', which DPOs bring in terms of expertise, peer support and the ability to work with 'hard-to-reach' groups. Increasingly DPOs are losing out on contracts for services that they originally developed such as independent advocacy and direct payments. This is in spite of a 2006 Protocol agreed between NCIL and the Association of Directors of Social Services.<sup>4</sup>

<sup>4</sup> 2006 Protocol Agreement wording: "ADSS and NCIL continue to recommend to local authorities that they support the development and expansion of local, user-led support services. We strongly recommend that local authorities develop policies that foster a level playing field for disabled people's and carer's organisations to compete in the tendering process."

<sup>5</sup> Maynard-Campbell et al (2007) Mapping the Capacity and Potential for User-Led Organisations in England. London: Department of Health.

### **Skills and expertise within DPOs**

It is apparent that DPOs possess a range of valuable skills and expertise.<sup>5</sup> Many DPOs have attained national quality standards, such as Community Legal Services Quality Mark and Investors in People. However, it is arguably their additional skills and expertise to deliver services that genuinely empower that are most valuable. It is this expertise that should give DPOs their competitive edge in relation to other third sector and private organisations, with which DPOs are increasingly competing for contracts.

### **Governance and leadership**

The DPO sector is also facing a crisis in leadership. In their responses to the Disability LIB research, many DPOs reported difficulties in recruiting management committee members and attracting younger disabled people. Those currently in leadership positions were often so stretched that they have no time to share skills and expertise or develop the next generation of leaders.

### **Capacity-building support**

Capacity-building support for the voluntary sector has not addressed the specific needs and identity of DPOs, consequently they have not been able to take advantage of the increased capacity-building investment aimed at third sector organisations.

## Chapter 3 - Thriving not Surviving

Despite a political climate that is quite favourable to DPOs, many DPOs are not thriving, and some are barely surviving. This chapter examines some of the key issues DPOs need to address in order to become a sustainable, joined-up sector able to proactively and effectively represent the rights and interests of disabled people long into the future.

These four key challenges are:

1. The extent to which DPOs should engage in formal service provision as a means of achieving their aims.
2. The level and nature of formal co-operation between DPOs necessary to achieve stability and growth for the DPO sector as a whole.
3. Strategies for attracting and retaining the next generation of leaders of the Disabled People's Movement.
4. The extent to which DPOs should engage more proactively with the third sector in order to benefit mutually from both sectors resources.

### Service provision as a means of achieving DPO aims

Many DPOs see moving into, or increasing, service provision as a key way to influence equality in practice and a route out of financial insecurity. The market for services for disabled people is expanding, thanks in no small

part to the DPOs and disabled individuals who fought to give disabled people autonomy over the support they receive through concepts like independent living, direct payments and individual budgets.

However, many DPOs have little experience or expertise in business development or social enterprise. Becoming a service provider sometimes feels like the only solution to the problems facing DPOs but this assumption needs to be examined and resisted where necessary. Many are not set up to provide services and would require significant organisational and structural changes to make this possible. For some a move into formal service provision would clearly divert them from their original aims and core values.

### Formal co-operation to achieve long-term stability

Inter-necine fighting is a little talked about but ever-present reality within the Disabled People's Movement. Clashes of ideology and personality are inevitable in a highly politicised movement, spearheaded as it is, by a small number of individuals with strong personalities and deeply held convictions.

The precarious financial situation of many DPOs makes the need for improved co-operation all the more urgent. Although DPOs are essential to the effective implementation of a whole raft of government policies Government has not yet taken steps to address the

financial crisis engulfing DPOs. Consequently the onus must be on DPOs themselves to design strategies to guarantee their long-term existence and expansion.

This will be a challenge. It will require an unprecedented degree of co-operation and trust between organisations but ultimately the future of DPOs will depend on being able to work together to protect and develop a strong, independent, mutually supportive DPO sector.

### **Attracting and developing the next generation of DPO leaders**

It is clear that whatever DPOs do next, a major priority must be addressing their leadership crisis. There are 11 million people in the UK who are protected under the DDA, yet only a tiny handful of these people are involved in the Disabled People's Movement. This is arguably the most important point in this paper, because without disabled people to lead it, the Disabled People's Movement cannot exist.

Young people are conspicuously absent from the overwhelming majority of DPOs, due to a combination of social exclusion, disaffection with 'old-fashioned' organised identity politics and increased inclusion in mainstream society. If DPOs are to achieve their aims of liberation and equality for disabled people they need to find ways of winning over the majority of their constituency and not just the young.

### **Tackling Disablism within the Third Sector**

The impact of disablist policies, attitudes and institutions are well-documented in society at large. What are not so well-documented and analysed are the levels of exclusion experienced by organisations of disabled people from the traditional charity or third sector, including the intermediary or co-ordinating organisations.

It is clear that a dialogue between DPOs and third sector coordinating organisations is urgently needed to tackle disablism across the sector and to gain access to the valuable expertise housed within the DPO sector which will be of benefit to all.

## Chapter 4 - The Future

It is clear from Chapter 3 that DPOs have reached a point where they need to make some difficult and important decisions about their future. The continuing need for an active, vocal DPO sector is evident, but their ongoing survival is far from guaranteed.

To make the right decisions DPOs must understand and adapt to the changing political and socio-economic environment and identify where they can add most benefit, while staying true to their core values. DPOs themselves must determine their own priorities and define the terms of their own recovery. Given the pressures on DPOs and the lack of mainstream appreciation for their value, one thing is clear. To succeed, DPOs need to recognise that their greatest allies are other DPOs.

However, DPOs cannot succeed alone. Once they have established the direction they wish to take they will need support to get there, from government, the third sector, the private sector and, if they so choose, disability charities. Some DPOs have already managed this transition very successfully; many others need help to do so.

The need to redefine the role of DPOs and develop the criteria necessary to realise an effective and sustainable sector were the motivations for developing the Disability LIB alliance. This unique partnership, led and

controlled by disabled people, will examine the current status of DPOs, their role and development opportunities. Their agenda for action is laid out below:

### Agenda for action

The Disability LIB alliance believes that the following need to be in place if the disability voluntary and community sector in England is to be more effective the profile of the sector is to be raised; and DPOs have access to vital infrastructure support and services that support their activities.

- 1 Increased access to mainstream capacity-building training and information free from the financial and physical barriers that exclude many DPOs from participating; recognising the multiple barriers to participation experienced by BME DPOs and DPOs that support people with learning difficulties and other marginalised groups of deaf and disabled people.
- 2 Increased number of disabled people amongst the staff and the trustee board of mainstream capacity-building organisations, and the third sector more widely, to ensure a diverse workforce representative of the community and where disabled people are in positions of power and influence.
- 3 Ensure that DPOs are given the opportunity, funding and support to contribute to, and influence, consultations and other public policy

initiatives that impact on their development.

- 4 Provision of relevant and appropriate support to DPOs to ensure they can bid and tender for contracts/funding on a level playing field, recognising the limited infrastructure of many organisations and the additional cost of being a disabled-led and -staffed organisation, and how this makes it difficult to compete with larger disability charities.
- 5 Ensure that DPOs, who, as user-controlled organisations, are preferred suppliers for contracts to provide disability specific activities, such as disability equality training, peer support, accessibility audits and direct payments.
- 6 Provide specific funding and support for the six key areas of development need:
  - management and governance
  - business skills and social enterprise
  - opportunity to adequately engage with and influence decision-makers
  - networking
  - involvement and inclusion
  - developing the next generation of leaders

The approach outlined above is the first stage of what will be a long-term journey to stability and sustainability for DPOs. This approach seeks to lift DPOs

out of survival mode and give them the support, time and skills they need to begin to create a long-term strategy for development and growth.

In light of this, the second part of this chapter offers some suggestions for possible organisational models that DPOs might consider when thinking about how they organise themselves both as individual organisations, and collectively as a sector. Getting out of survival mode is the first step to achieving long-term sustainability and growth. But new aims, and ways of working, may also require new organisational structures.

Below we outline five possible models that offer different approaches to moving forward the concept of mutual support and co-operation that would offer support for DPOs in key areas. The five models outlined below are not mutually exclusive and elements of all could be combined together if appropriate. It's also important to remember that they are only models and the examples given are not an exact fit for any specific DPO. However, it is clear that separating out the needs of DPOs from the needs of disabled people is desirable, as is some form of restructuring of the DPO sector.

### **Model 1 - The Co-operative Model**

The co-operative is a well-established organisational model dating back to the 19th century. A co-operative is a legal entity owned and controlled by its members and is based on the values of

self-help, self-responsibility, democracy, equality, equity and solidarity. This model would require DPOs to join forces to create a co-operative, at a local, regional or even a national level. A national DPO co-operative would be a very ambitious project but potentially worth it given the economic advantages that economies of scale could provide and the political influence a single national organisation of disabled people could exert.

### **Model 2 - The Alliance Model**

This model is a more pragmatic response to the short-term problems of inadequate DPO funding. Individual DPOs establish alliances with local, regional or national organisations where there is felt to be potential for mutual benefit. The ally could be a disability charity, a local authority, a business or even a football team.

An alternative, especially at a local level, might be an alliance with a resource-rich business that wishes to support a local organisation as part of its corporate social responsibility agenda rather than in exchange for specific services.

### **Model 3 - Sharing Services Model**

This very simple model involves local DPOs coming together to share services like finance, marketing and recruitment, which it is not financially viable to have in-house. A variation on this is joining together with other organisations in order to negotiate discounts on orders over a certain threshold. Many organisations already do this as a

means of efficiently reducing costs while getting access to professional services that many small voluntary sector organisations usually can't afford.

However, organised on a larger, even national scale, this model could give DPOs access to a much broader range of services and practical professional support as opposed to just advice.

### **Model 4 - The Trade Association Model**

A trade association is generally a public relations organisation founded and funded by corporations that operate in a specific industry. Its purpose is generally to promote the industry through PR activities such as advertising, education, political donations, lobbying and publishing. At first glance this model doesn't seem especially relevant to the development of DPOs. However, if you think about DPOs as an industry like any other, that disabled people want to protect, the value of an organisation dedicated to promoting and publicising the work of DPOs and representing their business interests at a national level is attractive.

### **Model 5 - The Enterprise Model**

This model is based on providing goods or services in order to make a profit. Activities are undertaken only if they are profitable, and organisations would not necessarily see disabled people as their exclusive consumer base. This is effectively a business model, and would fall under the category of a social

enterprise or a public limited company rather than a charity.

The five models outlined above are not mutually exclusive and elements of all could be combined together if appropriate. It's also important to remember that they are only models and the examples given are not an exact fit for any specific DPO. However, it is clear that separating out the needs of DPOs from the needs of disabled people is desirable, as is some form of restructuring of the DPO sector.

## Chapter 5 - A Statement of Common Understanding

The landscape in which DPOs are operating is changing rapidly. The DDA 2005 put a duty on public authorities to proactively promote disabled people's equality; the government has made a public commitment to achieve equality for disabled people by 2025 which includes establishing a user-led organisation in every locality by 2010; and the UN Convention on the Rights of Persons with Disabilities, signed by the UK in March 2007, provides a new framework for understanding and protecting disabled people's human rights. However, despite these advances many DPOs are struggling to survive.

It is clear that for DPOs to thrive rather than just survive they need not only to work together but to work with allies outside the DPO sector. Disability Charities, the wider third sector, local and national Government all have a crucial role to play in ensuring DPOs can be an effective, sustainable and vocal champion of disabled people's rights across the UK and internationally.

With this in mind, we have drafted the following Statement of Common Understanding. This develops the ideas articulated in the 2004 Statement of Collaboration between Scope and DPOs and attempts to define a set of principles that will better enable disabled and non-disabled people to work together as allies to deliver equality and justice.

We hope that other organisations will feel able to join Scope and the Disability LIB partners in signing-up to these principles as an indication of their desire to become a genuine ally of disabled people and their organisations.

### Statement of Common Understanding

- 1 We recognise that disabled people do not yet enjoy equal citizenship.
- 2 We accept that society's economic, political, social and cultural structures and attitudes need reorganising to empower and liberate disabled people so they can enjoy equal citizenship.
- 3 We believe that disabled people have the right to lead their own struggle for emancipation and full human rights now and in the future.
- 4 We believe that Disabled People's Organisations should be the vehicle for bringing together disabled people to define, organise and lead their own struggle for emancipation and full human rights, including re-visioning and reorganising society's economic, political, social and cultural structures and attitudes.
- 5 In a rapidly changing world, where demographic changes and advances in technology and genetic science have the potential to impact significantly on disabled people's lives, we recognise that DPOs are vital to provide a voice for disabled people and to safeguard their rights now and in the future.

6 We believe that non-disabled people, their organisations and government have a responsibility to support disabled people on their journey towards equality by learning how to be effective allies of disabled people and their organisations.

7 We believe that DPOs have a responsibility to work with non-disabled allies to progress disabled people's civil and human rights and achieve equal outcomes for all.

The above statements are made in light of our unwavering commitment to human rights, in particular, the principles laid down in the UN Convention on the Rights of Persons with Disabilities.

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This is one of the highest awards under Round 1 of the BASIS programme and is a significant endorsement of both the scale of the issue as well as the collective ability of the alliance to deliver such a ground breaking and innovative project.

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