C28897 Disability LIB Report 2/4/08 13:03 Page b/c2

Disability

Listen Include Build

C28897 Disability LIB Report 2/4/08 13:03 Page f/c1

Disability
Listen Include Build

Thriving or Surviving:

Challenges and Opportunities for Disabled People's Organisations in the 21st Century

Published by Scope in February 2008
on behalf of Disability LIB alliance

C28897 Disability LIB Report 2/4/08 13:03 Page i/fc2

Disability LIB
Listen Include Build

This report is dedicated to the thousands of disabled activists, most of whom remain unnamed and unrecognised, whose tireless work in defence of disabled people's rights has made the UK home to a range of such vibrant and diverse Disabled People's Organisations.

Acknowledgements

The Disability LIB alliance partners would like to thank all the individuals and organisations that contributed to, or gave valuable feedback on, this report or the research that informs it.

Particular thanks go to:
Ruth Scott, Richard Parnell, Sarah Reardon, Ruth Bashall and Mark Harrison who authored this report.

Emason and Pilotlight for the support they have given the Disability LIB alliance partners in developing the Disability LIB project.

Particular thanks also go to:
The Big Lottery Fund for their total funding of £4,245,382 for this project under their BASIS programme (Building and Sustaining Infrastructure Services).

LOTTERY FUNDED

The Disability LIB alliance partners are:
Alliance for Inclusive Education, Disability Awareness in Action, Equalities National Council, People First, Preston DISC, Scope and UK Disabled People's Council

Published by Scope, on behalf of the Disability LIB alliance, February 2008
Copyright Scope, 6 Market Road, London, N7 9PW
All rights reserved
ISBN: 094682881

C28897 Disability LIB Report 2/4/08 13:03 Page 4

Chapter 1 – What are Disabled People's Organisations and why do they matter?

The extent to which disabled people are excluded from our society is well-documented. In a disablist world, where even a disabled person's right to exist is not guaranteed[4], DPOs were created by disabled people as a vehicle to challenge the conscious and systematic exclusion of disabled people from mainstream life. DPOs were the first to articulate the view that disabled people are human and to champion the right of disabled people to be treated as full citizens with full human rights.

Though the first UK DPOs were established in the 1890s, it was not until the 1980s that modern DPOs really became established. The fact that DPOs took so long to come about reflects the pervasive nature of disability discrimination and its destructive influence on disabled people's sense of self, their ambitions and entitlements.

This results in what Micheline Mason describes as internalised oppression:

"Internalised oppression is not the cause of our mistreatment, it is the result of our mistreatment. It would not exist without the real external oppression that forms the social climate in which we exist.

Once oppression has been internalised, little force is needed to keep us submissive. We harbour inside ourselves the pain and memories, the fears and the confusions, the negative self-images and the low expectations, turning them into weapons with which to re-injure ourselves, every day of our lives."[5]

A brief history of the Disabled People's Movement

In order to put the development and achievements of DPOs in context it is helpful to provide an overview of the history of disabled people and their organisations and examine how they have shaped, and been shaped by, key social, political and cultural developments. An understanding of the way disabled people were viewed and treated historically by the non-disabled majority is crucial to understanding the development of the Disabled People's Movement and its current situation. The history of disabled people and the

[4] Disability is different to other equality agendas in that the issue of the right to exist looms large. Whereas these arguments have largely been won in the other diversity areas the concept that disabled people's lives are of equal value is still not widely accepted. There are numerous examples of this including: When a parent kills a disabled child it is presented in the press as a 'mercy killing'; it is not uncommon to terminate a pregnancy because a child has a cleft palate, a club foot or fused toes; disabled people admitted to hospital for routine procedures regularly find 'do not resuscitate' added to their notes without their consent; it is still acceptable to sterilise disabled people; the Royal College of Obstetricians and Gynaecology still debate the merits of active euthanasia of disabled infants on the basis of a clinician's assessment of what constitutes a 'useful life'.

[5] Mason M (1990) Internalized Oppression in Disability Equality in Education, Reiser R and Mason M (eds) London: ILEA.

C28897 Disability LIB Report 2/4/08 13:03 Page 5

Disabled People's Movement has been written about extensively by disabled activists; consequently our overview in this document is intentionally brief.[6]

Disabled people's history is characterised by absence. Disabled people as active historical agents are rare and, where they do exist, their impairments are either actively concealed or highlighted, usually to illustrate their weakness or evil character.

The history of DPOs also needs to be considered in light of other emancipatory movements. The 'absence' of disability in the history of mainstream social movements is compounded by the absence of disability from social theory. A trawl through four key social theory and sociology texts of the late 20th century reveals a complete absence of disability as a social issue.[7] This does not come as a surprise; despite the advanced understanding and debate around identity politics, few people consider disability or impairment to be an aspect of identity in the same way as class, gender, sexual orientation or ethnicity.

However, disabled people have always featured in the history of formal state organisation albeit in a negative way. The view established in the 14th century that disabled people constituted the 'deserving poor', incapable of work and therefore eligible for charitable alms, has been passed down through the generations and still informs much of mainstream society's view of disabled people today.

The first DPOs were established in the late 1800s. The British Deaf Association was established to promote sign language and quality deaf education in response to the banning of sign language in deaf education by the Milan Congress in 1880. The National League of the Blind and Disabled was founded soon after as a trade union, motivated by the desire to improve pay and working conditions for disabled workers.

The politicisation of DPOs increased during the first half of the 20th century, influenced by the large numbers of disabled war veterans from the two world wars and the rise of other liberation movements such as the Suffragettes, the Civil Rights movement in the USA, the Women's Movement and the anti-racist struggles in the UK and worldwide. A number of the founders of Union of the Physically Impaired against Segregation (UPIAS), founded in 1976, were anti-apartheid and feminist activists and brought their experience of these struggles to the Disabled People's Movement.

As disabled people began to acquire the language of rights during the 1960s and '70s, the focus shifted from welfare

[6] Key texts by Mike Oliver, Jane Campbell et al can be found in the selected bibliography.
[7] Sociology by Antony Giddens; Contemporary British Society by N Abercrombie et al; A History of Sociological Analysis by T Bottomore and R Nisbet; and Sociological Theory by L Croser and B Rosenberg.

C28897 Disability LIB Report 2/4/08 13:03 Page 6

towards equality. Equal civil and political rights became the driving force, and DPOs sprang up to challenge the power and dominance that non-disabled people and their organisations exerted over disabled people.

During the 1970s and '80s 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 (Oliver 1984). Disabled people began to self-organise locally, nationally and internationally in large numbers and the phrase 'nothing about us without us' was coined to articulate the Disabled People's Movement's core values.

These values – including independence, choice and control, self-determination, non-segregation, equal opportunities, inclusion and access to adequate resources – underpinned a concerted effort to win legal rights and protection from discrimination. The Disability Discrimination Act 1995 was a major victory for the Disabled People's Movement in the UK. After decades of struggle, and though flawed and incomplete, the DDA finally gave disabled people basic rights.

Since then, anti-discrimination legislation has been significantly strengthened, though there is still considerable room for improvement both in scope and in enforcement.

The Conservative Government passed the Disability Discrimination Act in 1995, and the Labour Government extended it. More recently, the Government has signed, though not yet ratified, the UN Convention on the Rights of Persons with Disabilities and has made the ambitious commitment to achieve equality for disabled people by 2025.

With basic rights secured in law, the role of the Disabled People's Movement and DPOs is 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.

A brief timeline[8]

1388 The Statute of Cambridge ("Poor Law") distinguishes between the 'deserving' and 'undeserving' poor claiming alms. Disabled and older people are considered to the 'deserving' and therefore eligible for charity.

1530s The dissolution of the monasteries creates large numbers of beggars, many of them disabled people who had previously been supported by the church. In response the Poor Law Act of 1535 decrees that 'the poor and impotent' should be supported by way of voluntary and charitable alms raised locally. This was the beginning of taxation to support the poor.

1547 Priory of St Mary of Bethlehem (which later becomes the infamous

[8] Extracted from timeline by Pete Millington, Disability West Midlands.

C28897 Disability LIB Report 2/4/08 13:03 Page 7

Bedlam Hospital) is given to the City of London for the express purpose of housing 'mental patients'. This is the first formal 'institution' for disabled people in England.

1601 Elizabethan Poor Law explicitly defines 'deserving poor' as disabled people and children – this sets the tone for the next 300 years of 'state administration' of disabled people's lives. Disability was characterised as an individual's problem and the state's role was to 'manage' them. Many amendments to the Poor Laws follow.

1750 The Industrial Revolution in Britain brings urbanisation and the breakdown of rural state and church welfare. The spread of poverty in cities leads to a growth in the number of institutions, asylums and workhouses to keep the 'economically unproductive' off the streets.

1868 The Royal National Institute for the Blind (RNIB) formed. This marks the beginning of modern charitable organisations, established by philanthropists or parents and carers, 'for' disabled people.

Late 1800s First DPOs are formed – in 1890 the British Deaf Association is founded, and in 1899 the National League of the Blind and Disabled is established as a trade union.

1920s More unions of disabled war veterans are formed and blind workers march against poor pay and conditions.

1939-41 Between 75,000 and 250,000 people with intellectual and physical impairments are systematically murdered by the Nazis through the Aktion T4 'racial hygiene' programme. As a precursor to this, 1933-39 saw the German authorities forcibly sterilize 360,000 disabled Germans.

1942 The Beveridge Report published. The economist Sir William Beveridge calls for a new social insurance system to conquer the 'five giants' of Want, Ignorance, Squalor, Idleness and Disease.

1948 The National Health Service Act and the National Assistance Act passed. The Labour Government constructs the 'welfare state' with the introduction of the National Health Service and the National Insurance Scheme. The welfare state marks the end of the 'deserving poor' charitable approach to disabled people, but the philosophy endures.

1940s and 50s Leonard Cheshire, RNIB and the Spastics Society establish residential homes for disabled people. Prior to this in the early 20th century and before the only option for disabled children and adults was to be (forcibly) put into mental institutions[9]. (Humphries & Gordon 1992)

1951 Greater London Association of Disabled People (GLAD) set up.

[9] Humphries S and Gordon P (1992) Out of Sight: Experience of Disability 1900 – 1950. Plymouth: Northcote.

C28897 Disability LIB Report 2/4/08 13:03 Page 8

1965 The formation of Disablement Income Group (DIG).

1966 Disability Rally in Trafalgar Square, London.

1969 The independent living movement begins in Berkeley, California. Ed Roberts and his associates set up the Disabled Students' Program on the UC Berkeley campus and establish the first Centre for Independent Living (CIL) for the community at large.

1970 Chronically Sick and Disabled Persons Act.

1971 Association of Disabled People (APG) established.

1972 Paul Hunt writes a letter to The Guardian newspaper calling for equality for disabled people. His letter inspires the start of a united struggle against discrimination.

1973 Spinal Injuries Association (SIA) formed. This is one of the first impairment-based charities to be run by disabled people.

1974 Union of the Physically Impaired Against Segregation (UPIAS) is formed and moves the focus away from welfare towards rights. UPIAS is the first to articulate the social model of disability, defining disability as: "the disadvantage or restriction of ability caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities."[10]

1976/77 Sisters against Disablement is founded by disabled feminists to promote disabled women's concerns and perspectives within the disabled people's movement. Several members were founders of UPIAS.

Early 1980s The first UK Centres for Independent Living (CILs) established in Hampshire, Derbyshire and Greenwich.

1981 International Year of Disabled People (IYDP).

1981 Disabled People's International is formed as a reaction to the refusal of The Rehabilitation International to share power with disabled people. British Council of Disabled People (BCODP) is established as an umbrella body that supports and encourages the development of hundreds of new organisations controlled by disabled people across the UK during the 1980s.

1982 The Commission on Restrictions Against Disabled People (CORAD) report advised that there should be legislation and a Commission to implement it. This was turned down by the Government, but CORAD began the campaign for civil rights legislation that culminated in the Disability Discrimination Act.

1988 People First founded.

[10] UPIAS (1976) p14.

C28897 Disability LIB Report 2/4/08 13:03 Page 9

1990 The first Black Disabled People's Network and several black mental health user groups are founded.

1991 Regard is founded to challenge homophobia in the disabled people's movement and the exclusion of disabled people from the Lesbian, Gay, Bisexual and Transgender (LGBT) community.

1992 Disability Awareness in Action established to support disabled people's self-advocacy empowerment internationally and promote and protect disabled people's human rights.

1993 Disability Action Network (DAN) formed.

1994 Sir Nicholas Scott, Minister for Disabled People, defeats the Civil Rights (Disabled Persons) Bill by procedural means at report stage.

1995 After years of campaigning by disability activists, the Conservative Government introduces legislation to outlaw discrimination against disabled people. The DDA is limited in scope and the duty to treat people equally is subject to a reasonableness caveat. The definition of disability is based on the medical model.

1996 BCODP establishes the National Centre for Independent Living (NCIL) to promote independent living options for disabled people. Concerted lobbying by BCODP's Independent Living Committee since 1989 results in The Community Care (Direct Payments) Act which creates direct payments.

2000 Disability Rights Commission (DRC) established.

2005 The DDA amendment act extends anti-discrimination protection to land transport, small employers and private clubs, extends the definition of disability and introduces a public duty to promote disabled people's equality and 'involve' disabled people.

The Prime Minister's Strategy Unit publishes its report, Improving the Life Chances of Disabled People, setting out recommendations for achieving disabled people's equality by 2025. Recommendation 4.3 of the report says that by 2010 there should be a user-led organisation, modelled on a Centre for Independent Living, in every locality.

2007 The UN Convention on the Rights of People with Disabilities opens for signature. UK Government agrees to roll-out individual budgets nationally.

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 and have an implicit or explicit commitment to the human rights of disabled people.

Technical definitions focusing on management structures or the ratios of disabled to non-disabled people do not

necessarily capture the essence of what it is to be a DPO. Recognising the complexity of arriving at a uniform definition of a DPO, Mapping the Capacity and Potential for Used-Led Organisations in England states:

"Defining a DPO is not clear-cut. The issue is not just a group's formal constitution. Some groups have no formal constitution, but are DPOs in practice. Others have a formal constitution, which defines them as a DPO, but over the years the power has shifted to non-disabled staff or volunteers. Others have all the 'right' formal arrangements, but work to a medical model of disability and do not promote the rights of disabled people, or practice inclusion."[11]

Both Preston DISC and Equalities found that many of the disabled people's groups they surveyed do not know what a DPO is or why this is an issue:

"A common misperception [amongst groups surveyed] is that if you had disabled people as service users you were a DPO."

The Mapping the Capacity and Potential for Used-Led Organisations in England research published by the Department of Health also differentiates between a user-led and a user-controlled organisation.

"The underlying issue of where the power within an organisation actually lies, complicates the picture further. There can be an organisation where users are clearly in the majority, but one person, whether disabled or not, can divert the organisation from its core values unless the governance arrangements are robust, and people understand and can effectively address balance of power issues." (Maynard-Campbell et al 2007)

Ethos is crucial to defining a DPO. The overwhelming majority of DPOs work to a 'nothing about us without us' model, explicitly or implicitly. This was the motto adopted by Disabled People's International at its founding in 1981, and captures the idea that human rights are not possible without self-determination. From this springs the principle of DPOs being led and controlled by disabled people – that disabled people should be in charge of their own organisations "making decisions, not following them".[12] DPOs seek to redress a history of disempowerment – of non-disabled people doing things 'for' disabled people, on their behalf, without their participation.

At their 2007 annual conference People First members said that disabled people needed to be in charge of their own organisations because:

[11] Maynard-Campbell S et al (2007) Mapping the Capacity and Potential for User-Led Organisations in England: A Summary of the Main Findings from a National Research Study commissioned by the Department of Health London: Department of Health.
[12] People First members at National Conference workshop 2007 – PF Stage 1 report page.

C28897 Disability LIB Report 2/4/08 13:03 Page 11

"...disabled people know best what we need, we can show people what we can do; we have never been in charge before, we make our own rules, it gives us more power, more control, skills and knowledge, more confidence."

Ensuring this balance of power throughout an organisation is difficult. Robust governance structures and 'top down' management can't deliver a respect culture on their own. Many DPOs attempt to achieve this balance by being highly democratic and deliberately non-hierarchical but even DPOs can sometimes find it difficult to manage the power balance between disabled people with different impairments. The 'hierarchy of impairment' is often cited as a barrier to DPOs being truly inclusive. For example, People First decided that their board must be 100% people with learning difficulties because, in their experience, on a mixed board those who don't have learning difficulties always dominate.

Given the difficulty of defining a DPO, it is helpful to outline what a DPO, or user-led organisation, definitely is not:[13]

- An organisation of 'interested parties' that runs a group 'on behalf' of its users
- A group of well-meaning people who raise money for trips, excursions or other non-rights focused activities for others
- An organisation that doesn't adhere to the governance or service delivery principles of a user-led organisation
- A local group that is governed nationally

Though it is difficult to capture the ethos and cultural attributes of a DPO within a formal definition the Disability LIB alliance has agreed on the following definition of a DPO, based on that used by Disabled Peoples' International (DPI):

"A DPO is an organisation whose constitution requires it to have a membership and managing board with a majority[14] of disabled people, and whose objectives are the rights and equality of disabled people."

Some DPOs consciously work to the social model of disability, or towards independent living. Some are not aware of the social model, but in practice work within it; some do not quite 'fit' the exact definition (e.g. many black and minority ethnic groups) but are committed to the rights of disabled people and to providing a voice of disabled people rather than for disabled people. In most cases DPOs are also committed to providing some form of peer support and empowerment to achieve independence and quality of life.

[13] Maynard-Campbell S et al (2007) Mapping the Capacity and Potential for User-Led Organisations in England: A Summary of the Main Findings from a National Research Study commissioned by the Department of Health London: Department of Health.
[14] Majority is defined differently depending on the DPO. People First requires 100% of its Board to be people with learning difficulties, UKDPC requires 75% disabled people; others only require 51%.

C28897 Disability LIB Report 2/4/08 13:03 Page 12

"The social model is, after all, about disabled people speaking for themselves and saying how society is disabling them. The experience will be different if you are black, an ethnic minority, lesbian, gay, or a woman and this needs to be taken into account."[15]

A social model focus also means working across impairment types or across medical labels – almost all BME, LGBT, women's and regional DPOs work across impairment. Of the 200 DPOs which the Disability LIB alliance has contacted, most are pan-impairment. People First, mental health system user groups and some BME groups work with a specific group of disabled people (such as those with mental health conditions, learning difficulties and sensory impairments) but do not divide people according to their medical label.

Disabled People's Organisations and disability charities

The wider disability sector encompasses a broad range of small and large charities and organisations, many of which are very well-established and well-known. These are commonly known as organisations 'for' disabled people, as opposed to 'of' disabled people. Most of them were originally formed by parents of disabled people, or non-disabled philanthropists, and employ a majority of non-disabled people.

These organisations tend to focus on providing services to disabled people and carers, though many now campaign as well. There are various types of 'for' organisations ranging from direct service providers such as Leonard Cheshire, Shaw Trust or Jewish Care to local branches of national charities such as Mencap, the RNIB or RNID, and a wide range of condition-specific groups like the Muscular Dystrophy Association and Diabetes UK. The latter tend to be smaller and focus on providing impairment-specific advice and information on treatment, care services and condition management. Many also conduct research into treatments and cures for specific impairments and conditions.

Most, but not all, of these groups work to a medical model of disability – i.e. they focus on managing, and in some cases curing, the impairment or condition rather than on making society adapt to fit the needs of disabled people. The numbers of these organisations are growing, with numerous local and national charities and trusts for each impairment type.

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

[15] Quoted in Count Us In 2000-2005 Report of the Disability Programme Trust for London 2005.

C28897 Disability LIB Report 2/4/08 13:03 Page 13

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 belief that disability charities were complicit in the continued oppression of disabled people was compounded by their reaction to the call for full civil rights. When disabled people initially called for a civil rights legislation in the 1970s, government and established disability charities did not support them, argued for diluted rights or in some cases actively opposed them. Even today some disability charities still describe disabled people as vulnerable people in need of protection rather than rights.

The antagonism between DPOs and the disability charities can also be explained by the huge disparity in the resources available to large disability charities and DPOs. The large disability charities have access to money, staff, time and marketing resources that enable them to exercise incredible power and reach compared to DPOs. The fact that many disability charities raise the money they need to maintain this hegemony using charity model fundraising messages further exacerbates DPOs' frustration. Addressing this power imbalance is a key motivation behind the formation of the Disability LIB alliance.

This legacy has understandably made DPOs wary of disability charities and in many cases actively hostile towards them. This is especially true now that some disability organisations argue that they fit the definition of a DPO as stated above. This creates unease, and anger, amongst many DPOs which highlight clear differences in the ethos, aims and approach of DPOs and disability organisations. Some disabled people argue that many disability organisations have simply adopted the language of rights but haven't adapted their structures, thinking or culture to match. Despite 'talking the talk' of rights they run services that do not always support equality, independent living and justice for their users. These organisational wolves in sheep's clothing are then able to compete with DPOs for scarce resources, threatening the very existence of some DPOs. This is a crucial point to which we will return later.

For many DPOs the right form of constitution and a commitment to rights and equality is not enough to make a disability organisation a DPO; but articulating and, crucially, measuring, these differences in ethos and approach is not easy. With the boundaries between disability organisations and DPOs becoming increasingly blurred, especially to those not versed in the language of disability rights, defining that distinction is more important than ever.

Until recently the disability charities have largely rejected the criticisms of DPOs and continued with 'business as usual'. This has created a chasm between 'of' and 'for' organisations with both sides' attitudes to the other characterised by

mistrust and antagonism. This impasse 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.[16] (Mills and Parker 2004)

The significance of this statement should not be underestimated. For the first time in the UK a number of DPOs and a major disability charity publicly agreed to collaborate in order to achieve equality, justice and full human rights for disabled people. Crucially, the statement recognised the traditional power imbalance between charities and DPOs and laid the groundwork for a new way of working together, based on partnership, openness and a shared ambition of full citizenship for disabled people.

It is not overly dramatic to say that without this statement, and the work that followed, the Disability LIB alliance, consisting of Scope and six DPOs, would not have been possible. It marked the start of a new era of co-operation and mutual understanding between historical enemies that will be of benefit to both. Crucial to this is Scope's explicit undertaking to become an ally of the Disabled People's Movement and individual disabled people. A true ally recognises the simple truth that disabled people are the legitimate leaders of the struggle for disabled people's emancipation and that they are the people who 'know best what disabled people want and need'. Understanding how to be an effective ally will take time, and no doubt there will be mistakes along the way. But the commitment to try and ultimately succeed is there.

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.

[16] Miller P and Parker S (2004) Disablism: How to tackle the last prejudice page 17. London: Demos.

C28897 Disability LIB Report 2/4/08 13:03 Page 15

The Human and Civil Rights of Disabled People: Statement of Collaboration

Sharing a common anger at this situation, and acknowledging that we are all working within our own spheres to effect social change, we believe that it is important to grasp an opportunity to work together to:

- find collaborative solutions to ensure disability rights are pushed further up political and social agendas, and mainstreamed within national and local policy
- challenge the barriers faced by disabled Britons
- explore the potential for new partnerships.

We are united in wishing an end to institutional disablism and the enforced segregation of disabled people.

We are all committed to the full and equal participation of disabled people as citizens of the UK.

We acknowledge that we are coming to this unity and commitment from different perspectives and agree to observe the dignity and expertise of each of us equally. We recognise that our diversity offers a source of real strength.

However, we acknowledge that the voice of disabled people themselves has, traditionally, been left out of planning policies and programmes that directly affect them.

Therefore, we believe that this voice must be positively supported and should provide a leading role in our collaboration.

We also acknowledge that, historically, there has been an unfair distribution of resources – and the resulting power structures – between the disability rights movement and the large charitable disability organisations.

Therefore, we will take that imbalance into consideration.

We are therefore committed to collaborating, because we believe that working together we must achieve more to advance our common goal – that disabled people achieve the full human and civil rights that should be enjoyed by all Britons irrespective of difference.

C28897 Disability LIB Report 2/4/08 13:03 Page 16

Chapter 2 – The Status of Disabled People's Organisations in Great Britain

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

- Being a voice of disabled people – representing disabled individuals and groups
- Influencing local and national policy and service providers
- Campaigning, e.g. on equal access to the built environment, health care and independent living
- Supporting disabled people to be involved in local forums and influence policy and practice

Providing services

- Information and advice on issues such as benefits, legal rights, equipment, local service availability
- Independent advocacy and help in accessing services
- Leisure and arts activities
- Support with employment and training
- Support to access Direct Payments and independent living support
- Translation into community languages, transcription into accessible formats for members
- Training (Disability Equality, Independent Living)
- Services to businesses and public sector (access audits, advice and consultancy on the Disability Discrimination Acts)

Peer support

- Self-help, networking and support
- Support to self-advocate
- Peer support and mentoring
- Youth work (very few groups provide this)
- Supporting local groups of disabled people

Some DPOs work with all disabled people while others focus on communities of interest. Communities of interest include disabled people from minority ethnic groups, lesbian, gay, bi-sexual and transgender disabled people, disabled women, people with learning difficulties, mental health service users, young disabled people and older disabled people. In general all DPOs undertake activities that fall into one or more of the categories outlined above, though DPOs focused on

C28897 Disability LIB Report 2/4/08 13:03 Page 17

communities of interest will also look at issues of identity and the inclusion of their particular group in the mainstream Disabled People's Movement.

Types of DPOs

The DPOs surveyed by the Disability LIB alliance partners include: 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.

Categorising DPOs

Given the sheer numbers of DPOs, it is difficult to fully map the sector. Mapping the Capacity and Potential for User-Led Organisations in England report identified over 1,000 user-led organisations in five areas of England, with 90% of localities having up to 15 each. It is likely that this is an underestimation, because of the number of small local groups, which come and go or have no formal contact with a larger DPO but are linked to general, local or regional networks. This may be particularly true of Black and Minority Ethic groups (BME) and Lesbian, Gay Bisexual and Transgender groups (LGBT) and other 'communities of interest', which are not specific to one local authority area. it may also be true for groups in areas where there is no larger DPO acting as an 'umbrella' to the smaller groups.

"Currently there is limited hard evidence and little specific research at local, national or regional level that can be used to accurately determine the numbers of BME DPOs in England."[17]

It is possible to group DPOs across England into four broad categories, recognising that size and resources do not necessarily match what they do. For example, some national organisations have no paid staff, no premises and little or no funding.

1. Unfunded small DPOs

These are usually small unfunded self-help groups, for example: impairment-specific groups; BME groups and networking groups. They generally operate from someone's house or a community centre and are run by volunteers. They have no paid staff and are unincorporated. As such they have no formal status, or constitution and no formal policies.

Most of these DPOs perform an essential support function for their members – for example, making information accessible to them in their own language, linking them into services or just breaking down social isolation. Many of these groups have no or very limited links with other DPOs or with the voluntary sector generally and are either funded through member contributions or via donations.

[17] Equalities National Council report on Disability LIB Stage One Research.

C28897 Disability LIB Report 2/4/08 13:03 Page 18

2. Small funded DPOs with an income of less than £15,000 per annum

Small campaigning/lobbying DPOs such as access groups, self-advocacy groups of people with learning difficulties or mental health issues, some BME and LGBT groups, and many impairment specific groups.

These groups usually have a basic constitution, are linked into some local or national networks, and have working relationships with their local council or other statutory body (for example, through Partnership Boards); they have no paid staff but regular volunteers.

They may have been able to access minimal funding (for example, for meeting costs, or making information accessible) from statutory or charitable sources, sometimes via a third party organisation. Some do not have charity status but need it in order to expand. Some People First groups and BME groups fall into this category. Community of interest groups operating at regional or national level (LGBT disability groups such as Regard and Gemma, some BME networks, the Developmental Adult Neuro Diversity Association (DANDA) and so on) with minimal funding, operate both as social networks and lobbying groups.

In most areas there are also user-involvement groups which act as advisers to local and health authorities and occasionally to bodies such as the police or Regional Development Agencies. Some of these groups may aspire to become independent and would benefit from indirect support through sub-regional DPOs.

3. Medium to large funded DPOs

Medium-sized campaigning/lobbying, advocacy and self-advocacy organisations with one or two paid staff, charity status, and links into national and local networks.

Funded, fully constituted regional and sub-regional DPOs, which provide services to disabled people, support to smaller local DPOs, and lobby and campaign for the rights of disabled people. These include most 'umbrella' borough or county organisations of disabled people, Centres for Independent Living, and some of the larger BME groups such as Asian People with Disabilities Alliance or London Ethnic Minority Deaf Alliance. Many of these organisations are facing funding crises; a small number have closed recently.

4. National DPOs

Established, funded, national DPOs whose function is to lobby and act as a national voice for their constituency, as well as providing capacity-building and support to their member groups. All of these groups face difficulties with long-term, sustainable funding, and have capacity-building issues of their own.

The political climate

The wider political climate appears, on the surface, to be favourable to DPOs. There is an unprecedented focus on

C28897 Disability LIB Report 2/4/08 13:03 Page 19

user-involvement in service planning and delivery, particularly, but not only, around health and social care. There are also a range of high-profile initiatives aimed specifically at disabled people which recognise the importance of fully involving them. These include:

- **Improving the Life Chances of Disabled People**
  Perhaps most significant for DPOs is recommendation 4.3 of the highly influential 2005 Strategy Unit report Improving the Life Chances of Disabled People. This explicitly said that:
  By 2010 each locality should have a user-led organisation modelled on existing Centres for Independent Living.[18]

- **Duty to Promote Disability Equality**
  The Disability Discrimination Act 2005 places a duty on all public authorities to involve, rather than merely consult, disabled users of services in the development, implementation and evaluation of their Disability Equality Scheme. Consequently, there is a clear role for DPOs in helping public authorities meet their statutory duties under the Act.

- **Personal Budgets**
  Person budgets, also referred to as individual budgets and direct payments, are designed to put individual disabled and older people in control of deciding what support or services they get so they can achieve maximum independence. DPOs have been heavily involved in supporting the pilots for individual budgets, helping disabled people assess their own needs and make choices about the support and services they want to buy. Given that the government has already committed itself to rolling out personal budgets nationwide, DPO involvement in the long-term will be crucial to ensuring their success.

- **Valuing People**
  Valuing People is the Government's initiative for improving the lives of people with learning difficulties, their families and carers. It was the first White Paper for people with learning difficulties for 30 years. It covers the whole of England and is based on disabled people achieving:

  - their rights as citizens
  - inclusion in local communities
  - choice in daily life
  - real chances to be independent

- **Human Rights Act 1998**
  The Human Rights Act 1998 gives legal effect in the UK to 16 of the fundamental rights and freedoms contained in the European Convention on Human Rights (ECHR). The Act makes available in UK courts a remedy for breach of a Convention right, without the need to go to the European Court of Human Rights in Strasbourg.

[18] Strategy Unit, Improving the Life Chances of Disabled People 2005.
http://www.cabinetoffice.gov.uk/strategy/work_areas/disability.aspx

- **UN Convention on the Rights of Persons with Disabilities**
  On 13 December 2006, the United Nations formally agreed the Convention on the Rights of Persons with Disabilities, the first human rights treaty of the 21st century designed specifically to protect and enhance the rights and opportunities of the world's estimated 650 million disabled people.

- **UN Convention on the Rights of the Child (1989)**
  The Convention on the Rights of the Child is the first legally binding international legislation to incorporate the full range of human rights – civil, cultural, economic, political and social rights. The Convention spells out the inalienable human rights that all children (including those who are disabled) have throughout the world.

However, despite this seemingly favourable political climate, DPOs are in trouble. The research conducted by Disability LIB partners has revealed a sector in crisis. DPOs clearly possess significant skills and expertise for they deliver quality services and act as a much needed voice for disabled people in addressing exclusion and discrimination. But DPOs across England are facing a funding and leadership crisis.

Key challenges facing Disabled People's Organisations

Sustainable funding

Funding was always the first response to questions about key challenges from the DPOs interviewed as part of the Disability LIB project. Every DPO reported difficulties with getting funding, and not being able to provide essential activities or services because of a lack of funding. This is mirrored in Mapping the Capacity and Potential for Used-Led Organisations in England's report. (Maynard-Campbell et al 2007)

In the last 18 months there have been several closures of larger established regional or sub-regional organisations (such as Shropshire CIL and Greater London Action on Disability). One national organisation (the UK Coalition of People Living with HIV and AIDS) and other CILs are also under threat.

The Disability LIB partners' mapping exercise showed that across the country, small groups have closed. For example, Preston DISC, in their mapping of local disability organisations in the North West, found that in the five areas of the North West surveyed, 30 groups of and for disabled people had disbanded. Other groups are "in serious financial trouble", as People First found when mapping self-advocacy groups of people with learning difficulties. In some cases, this has pushed DPOs back into depending on non-DPOs such as national disability charities.

"The case studies show that smaller groups are managing on minimal funding and do not have the capacity to raise funds effectively. Few appeared to have a proper exit strategy when current funding ends."[19]

Other groups who work across local authority boundaries face even more significant barriers to funding. Community of interest organisations such as those led by BME, LGBT, Deaf or refugee and asylum seeker disabled people face double or treble barriers in accessing funding and being considered as equal players in competing for funding or contracts.

"Many of these groups do not operate within specific local authority geographical boundaries, so cannot access funding from that local authority, and they may not have the capacity to access wider funding."[20]

Barriers to securing funding

DPOs that took part in the Disability LIB Stage 1 research faced a range of barriers to obtaining funding including:

- Inaccessible application processes (for example, the requirement to complete application forms online, jargon and inaccessible forms) and deadlines and targets that don't take account of the additional time required by many DPOs to prepare bids and complete work.
- DPOs find it hard to compete with the major disability charities who have large fundraising and marketing departments with dedicated fundraisers who can attract income from a range of potential funders from individuals through to large corporate organisations.
- Few DPOs have access to advice and guidance on securing funding because training is not accessible or relevant to them.
- Short term project funding and the difficulties in getting funding to cover core organisational costs leads to significant financial insecurity and preparing new funding bids diverts precious resources away from project delivery.
- Lack of financial expertise and business planning skills make it difficult for DPOs to make effective grant applications and tenders.
- Some DPOs also struggle with operating proper financial systems which are essential to managing public funding and meeting conditions of grants.
- DPOs find that many funders place them under a 'social care' heading. As a result, DPOs are often forced to compete with other DPOs for the same pots of funding.
- DPOs do work for which it is hard to get funding, most significantly policy work, campaigning and advocacy. However, many feel forced to provide free consultancy because they fear

[19] Maynard-Campbell S et al (2007) Mapping the Capacity and Potential for User-Led Organisations in England: A Summary of the Main Findings from a National Research Study commissioned by the Department of Health London: Department of Health.
[20] Ibid.

demanding payment for their involvement might result in them being excluded from the decision-making process altogether. For example, at the UKDPC consultation event with member groups in June 2007, 10 of the 11 regional and sub-regional groups present had been closely involved in the production of their local authority (and in some cases their local health authority) Disability Equality Scheme. In some cases they were recognised for organising the consultation with disabled people, but only one DPO had received any additional funding for this work.

- Many DPOs will not apply for funds from the telethons such as Children in Need or Comic Relief or use 'tin-shaking' fundraising methods as they feel it reinforces the negative image of disabled people as objects of pity and charity. This limits the sources of income available to DPOs.
- Asking disabled people to pay for services or make donations towards the running of the organisation is often not practical or financially lucrative enough as disabled people most in need of DPOs support are usually least able to pay for it.
- Only a few DPOs have been successful in generating a profit from selling services, such as training, consultancy, audits and advice to businesses, to the private or public sector. Pilotlight's work with a London DPO shows that many DPOs have yet to develop the business skills necessary to generate real income for their organisation.

The extra cost of being a DPO

DPOs sometimes face substantial, additional costs because their staff or volunteers are disabled people or because they work with disabled people. This is not only about costs of resources, but the extra time needed to do the job well and to give disabled people control:

"Considerably more resources are needed for the process to work – mainly time and people, especially to support people from BME communities, people with learning difficulties and mental health system survivors, or Deaf Blind people: more home visits, more time for users to think about options, work to set up Independent Living Trusts or other support mechanisms etc. Different groups of disabled people need different levels of support and some take more time than others."[21]

A group of London-based DPOs have just got funding for a piece of work to quantify the additional costs of disabled staff. To date additional costs identified include:

- The cost of advertising in specialist accessible media
- The cost of additional space because of people's access needs (physical access, extra storage space for large print or Braille users)
- Additional costs of equipment,

[21] NCIL 2006.

communication and adaptations
- The cost of support workers or personal assistants
- Time and resources needed to support and supervise disabled staff who need training from scratch because of lack of previous employment experience
- The additional cost of sickness cover for staff with long-term health problems
- The lack of support from Access to Work for disabled volunteers
- The difficulties of getting adequate Access to Work support for disabled staff
- Additional costs associated with barriers in the mainstream: for example, staff having to use taxis because of inaccessible public transport systems

These additional expenses are not usually considered by funders or commissioners, but they add to overall costs and mean that bids may be rejected on grounds of cost.

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.

"Many local user-led organisations do not have the experience or resources to participate in, or to compete effectively with "larger organisations seen as a safe pair of hands."[22]

DPOs consistently report difficulties in winning contracts, even for services which they themselves set up, or where they first identified a need, such as direct payments support or an advocacy service. Statutory services may not see DPOs as 'professional enough' or as cost-effective. The inability to 'talk the talk' of business and contracts is one factor, as is the fact that many DPOs bidding for service contracts are also rights-based advocacy organisations and the statutory sector often considers the two to be incompatible. The fact that most DPOs work locally for local people also limits their opportunities for reducing costs through economies of scale.

Tendering processes are particularly onerous, and often not accessible. Timescales, use of jargon, inaccessible application processes and a requirement for a high level of liability insurance all disadvantage DPOs. Cost-effectiveness criteria do not take account of 'added-value', which DPOs bring in terms of expertise, peer support and the ability to work with 'hard-to-reach' groups. In the past three years for example, at least six DPOs in London boroughs, and large CILs, such as Hertfordshire PASS and Shropshire CIL, have lost direct payments contracts

[22] Maynard-Campbell S et al (2007) Mapping the Capacity and Potential for User-Led Organisations in England: A Summary of the Main Findings from a National Research Study commissioned by the Department of Health London: Department of Health.

to large voluntary sector businesses. This in spite of a 2006 Protocol agreed between NCIL and the Association of Directors of Social Services which states that:

"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."[23]

Starting up

Most small groups face difficulties starting up. Many start from the needs of a few individuals meeting in people's houses or in community centres. For DPOs, starting up is often a more complex process than it is for non-disabled groups as meeting in someone's front room is not an option if that room is not accessible to all members. Balancing member needs can be difficult. Before a group can start operating, it may need to get money for basic resources: transport for those who can't use public transport (especially an issue outside larger cities), an accessible venue, equipment such as an induction loop, access to a computer to produce large print, or BSL or community language interpreters, and in some cases support workers.

Often funding for these resources is impossible to obtain without a constitution, some basic policies, and the ability to submit grant applications, which even for small pots of money are becoming more and more formal. As a result, small groups start up and fold very quickly as they are unable to meet members' access needs. Those groups that are successful are often either single impairment, or have the support of a larger organisation, either a local DPO or occasionally a mainstream community centre.

Skills and expertise within DPOs

The range of valuable skills and expertise held by DPOs is apparent.[24] Some are common to all successful voluntary sector organisations: skills in management and planning, negotiation, finance, representation, consultancy and training, human resources, policy development and so on.

However, DPOs, their staff, volunteers and management committees have also developed a range of additional skills and expertise because of the specific focus of their membership and of their work. These skills include:

[23] Joint Protocol between National Centre for Independent Living & Association of Directors of Social Services for the provision of Centres for Independent Living and User Led Support Services.
[24] Maynard-Campbell S et al (2007) Mapping the Capacity and Potential for User-Led Organisations in England: A Summary of the Main Findings from a National Research Study commissioned by the Department of Health London: Department of Health.

- Involvement and consultation
- Working across difference
- Supporting individuals to take control
- Peer support, advocacy and empowerment
- An holistic approach to supporting individuals
- Creative thinking and the ability to find imaginative solutions to overcoming barriers for disabled people, such as in employment, access to information, access to services, housing and transport
- In-depth knowledge of relevant legislation and policy initiatives
- Understanding of how to make information and communications accessible.

A focus on working across impairments rather than fragmenting into impairment-based groups means that, more than for other voluntary sector organisations, DPOs have had to rise to the challenges of being inclusive. Successful DPOs focus on work across differences not only of gender, ethnicity or culture, sexuality and age, but also of impairment and of experience. For example, people with learning difficulties, working with people with acquired physical or sensory impairments, or the Deaf community. This has meant devising different ways of running an organisation. Self-advocacy has allowed DPOs to act as a focus for people to develop their own independent skills whilst supporting others to do the same.

The fact that many DPOs have attained national quality standards, such as Community Legal Services Quality Mark and Investors in People, shows the pool of professionalism there is within DPOs, and the potential for sharing skills across the sector. However, it is arguably their additional skills and expertise that are most valuable and that set them apart from other third sector and private organisations, with which DPOs are increasingly competing for contracts.

Getting mainstream commissioners to appreciate the value of this expertise is an uphill struggle, especially in the current economic climate where costs are being cut across the board. However, it is these skills and expertise that enable DPOs to deliver services that genuinely empower. It is this ability that should give DPOs their competitive edge, if they could 'sell' it.

Governance and leadership

The DPO sector is facing something of a crisis in leadership. In their responses to the Disability LIB research, many DPOs said they had difficulties recruiting management committee members, and were worried that when a current chair or director leaves, there is no-one to take over. This is particularly true for those organisations operating in 'survival' mode, where it is difficult for overburdened leaders to make space for skills sharing and mentoring. This leads to one or two people taking on too much responsibility and having no time to involve or develop others to share the workload.

Across DPOs, there are a number of effective chairs, chief executives, directors, paid staff, volunteers, and management committee members who have seen their organisation through a process of change and ensured its future. However, this represents a relatively small number of people, some of whom are on Management Boards of several organisations, and many of whom are getting older. In recent years DPOs have also lost key leaders to the statutory and third sectors or to advisory bodies (such as The Disability Rights Commission and Equality 2025) who pay people for work they previously did unpaid as chairs or management board members.

Younger disabled people, the natural successors to the current leadership, are poorly represented in DPOs. Leadership is mainly provided by older disabled people. There are some notable exceptions to this, for example, Greater Manchester Coalition and Newham Action and Rights, and some People First groups, but by and large the younger generation of disabled people are not 'connected' to DPOs – either because young disabled people have successfully become part of mainstream and cannot see the relevance of DPOs, or because young disabled people are still disempowered and marginalised by society.

Research by the Alliance for Inclusive Education (ALLFIE) research[25] showed that the concerns or ways of working of 'adult' DPOs are not those of younger disabled people. This helps to explain why DPOs find it difficult to attract and retain younger members.

Management committees in DPOs as much as in the rest of the voluntary sector are frequently dependent on the skills of a small number of people. Most people get involved because they want to put something back or want to campaign for the rights of disabled people, then find themselves having to make decisions about staff or finance. Disabled people have historically not been part of the management of voluntary sector groups – so have often not had a chance to acquire the skills necessary to run an organisation.

Finding suitably experienced disabled people willing to take on leadership roles is very difficult, especially at a time when the responsibilities of governing bodies are increasingly onerous. Often being on a DPO management committee is people's first experience of the voluntary sector, and they have to learn not only about being a DPO, but about governance and legal responsibilities. DPOs face difficulties getting funding for essential resources to support disabled board or management committee members.

The lack of accessible, plain English, Easy to Read or community language documentation and training is also a barrier. Committees and boards of third sector organisations face increasingly

[25] ALLFIE Disability LIB Stage One Research findings.

onerous legal responsibilities but if these are not made available to people in a format that is right for them, disabled people become reluctant to take on management roles.

Added to the low skills base is the reality of the lives of many of the people involved in DPOs:

"...Disabled children and young people are as excluded from the decision making process about their lives as ever before."

For those asked to join management committees, it is a big leap to find themselves having to make decisions about running an organisation. Smaller groups in particular are often dependent on the skills of one or two more empowered individuals. The process of developing decision-making skills through peer support and learning is a long, drawn-out process. For example, most People First groups have needed five years to become strong enough to be independent and employ a worker.

There are major issues of sustainability and continuity for organisations where key people have long-term health conditions, which mean they may be unable to be involved for long periods of time, or only stay for a short while, however committed they are. One organisation known to the Disability LIB researchers had lost half of its management committee in 18 months due to resignation through ill health or to the death of board members; and one national DPO has lost its Chair and a key member of staff in a period of three months.

Some organisations rely exclusively or mostly on volunteers and as a result the chair and officers have to take on considerable extra responsibilities. There are particular issues for those organisations that employ a non-disabled chief executive, where there are tensions around who has the power and control in the organisation, particularly where the social model principle of empowerment and decision-making is not fully understood.

The governance and legal arrangements for established DPOs have remained fairly static for many years, and in many cases do not reflect the changing needs of the organisation. There is an interest, for example, in social enterprises, but relatively little knowledge about what it means in practice.

Capacity-building support

Capacity-building support for the voluntary sector has not addressed the specific needs and identity of DPOs. In NCIL's words:

"The work that the government has been doing on capacity-building the voluntary sector has not identified the particular value and needs of user-led organisations [of disabled people]. For

[26] Ibid.

example, the Compact[27] has not identified the particular role of user-led organisations... nor has Change Up."[28]

As a result DPOs have not benefited as they should have from government investment in resourcing and supporting third sector organisations.

The Disability LIB alliance partners surveyed a wide range of DPOs to establish what their capacity-building needs were. DPOs identified needs which fall into six broad categories:

- **Management and governance** – management systems, people with the skills to manage, human resources, internal policies, skills for management boards, mentoring and coaching
- **Leadership** – developing a new generation of leaders and skilled disabled people to do the work of DPOs
- **Business skills** – financial and management systems and skills, how to win contracts, effective fundraising and income generation, and social enterprise
- **"Voice"** – information, how to act as representatives of disabled people, how to influence policy, how to campaign. Tackling discrimination, exclusion, stigma and human rights in the wider society and people's own communities
- **Networking** – sharing information and joint working
- **Involvement and inclusion** – being an inclusive, user-led organisation of disabled people: involving members, working together, diversity and tackling discrimination within organisations

The Disability LIB research has demonstrated that DPOs are excluded from most mainstream voluntary sector capacity-building initiatives, due to barriers and a lack of understanding of the user-controlled disability sector. Programmes like Change Up have bypassed DPOs. DPOs have had limited support and sometimes difficult relationships with local and regional Councils for Voluntary Service. DPOs themselves are often not aware of what these organisations or programmes could offer them. Where DPOs have tried to access these programmes, they have experienced considerable barriers including:

- Access and communication: inaccessible information and training courses, language and concepts that are not accessible, time-limited support that is insufficient to meet their needs, lack of transport and so on
- An approach to learning that does not meet the learning needs of some disabled people who prefer face-to-

[27] Full name – 'The Compact on Relations between Government and the Voluntary and Community Sector in England', first introduced in 1998, is the framework agreement for how the government and the sector should work together. It is an agreement between government and the sector to improve their relationship for mutual advantage and community gain.
[28] NCIL report on Centres for Independent Living 2007.

face discussion and dialogue to formal seminars or written documents
- Disability equality seen as a 'special needs' or social care issue not an issue for the whole voluntary sector
- A focus on dealing with professionals on behalf of disabled people
- A focus on business skills and formal structures
- Low value placed on experience and peer support
- Black and Minority Ethnic (BME) and Lesbian, Gay, Bisexual and Transgender (LGBT) DPOs are not supported by BME or LGBT capacity-building organisations or in some areas by larger white-led DPOs
- A 'one size fits all' approach, which does not take into account the uniqueness of user-led DPOs
- There is also some resistance and mistrust of non-disabled professionals, because they are seen to mirror disabled people's experiences in everyday life of being told what is best for them by non-disabled 'experts'.

As a result, those DPOs that do engage with the mainstream capacity-builders find themselves having to repeatedly address barriers and educate capacity-builders, rather than learning and gaining new skills from them. This experience is shared by the DPOs within the Disability LIB alliance and by the wider DPO sector.

Within the DPO sector itself there is considerable expertise in some aspects of capacity-building:

- There is wide-ranging expertise on setting up and running user-led DPOs
- Some larger regional and sub-regional DPOs are supporting smaller DPOs. They provide support around funding, managing staff, work and business planning, running meetings and so on
- DPOs' capacity for innovative thinking and problem solving is of great value in supporting new service provision
- There is a wide pool of expertise on specific aspects of capacity-building within DPOs, but these skills are not always shared because of the gaps in regional networks, particularly outside of major urban areas.

Many larger DPOs do not have the capacity to support smaller DPOs because their own survival is not certain and their resources are fairly limited. The lack of funding for 'development workers' for many years means capacity-building skills have been lost to some degree within the sector.

Some DPOs do access capacity-building support successfully. Mapping the Capacity and Potential for Used-Led Organisations in England's research shows that some of the more stable DPOs were those that had been able to access external capacity-building support, particularly through social enterprise networks. It is significant that these are recent networks whose job is to think 'outside the box'.

The work done by Pilotlight in Phase 1 of the Disability LIB project shows the

C28897 Disability LIB Report 2/4/08 13:03 Page 30

value of focused and skilled capacity-building support for DPOs. Two very different DPOs in London were able to benefit from the short-term capacity-building offered by Pilotlight, in particular in terms of business planning and a strategy for income generation. Participation in the steering group meetings has helped Pilotlight and Emason to learn about how the DPO sector works, and to understand the barriers it faces. The initial work shows that mainstream capacity builders and DPOs can work together using their individual strengths to meet the capacity-building needs of DPOs.

C28897 Disability LIB Report 2/4/08 13:03 Page 31

Chapter 3 – Thriving not Surviving

Despite a political climate that is quite favourable to DPOs, Chapter 2 shows that many DPOs are not thriving, and some are barely surviving. It is ironic that just as government policy starts to promote user-led organisations, many of these organisations find themselves on the brink of extinction. If the current rate of decline continues it is conceivable that by the time Recommendation 4.3 is implemented in 2010 there will be fewer DPOs in existence than when the Improving Life Chances research began.

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.

Key to this discussion will be four issues:

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.

1. Service provision as a means of achieving DPOs aims

One of the researchers who examined the capacity-building needs of DPOs involved in the Disability LIB alliance commented:

"To do more than survive, and to thrive as an effective voice for the disabled people's sector, DPOs have had to combine the traditional functions of social movement organisations (campaigning, lobbying, influencing policy, representation etc) with being service providers. Like most voluntary organisations DPOs face threats to their long-term survival, their funding and their role in speaking out for their own constituencies."

This observation gets to the heart of the dilemma facing DPOs. 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. This expansion is juxtaposed against increasingly fierce competition for grants and government funds amongst third sector organisations, making service provision all the more appealing.

Changes in government funding policies and practices have profoundly affected

the development of DPOs. The emergence of disability as a political issue and DPOs as a social movement in the 1980s, following on from the United Nations International Year of Disabled People (1981) and the birth of Disabled People's International, led to funding opportunities for organisations run and controlled by disabled people. DPOs received grants from national and local government and charitable trusts. Until recently UKDPC (formerly BCODP) received core funding from the Department of Health (DH). Since this was withdrawn the organisation has been unsuccessful in its attempts to get funding from the DH despite several attempts to do so.

Government attitudes also mirror this increased focus on services. The Office for the Third Sector's report published in July this year entitled The future role of the third sector in social and economic regeneration[29] has, as two of its key priorities, increased support for third sector organisations to deliver public services, and increased support for social enterprise. Government thinking on the role of third sector organisations in service provision was summed up by one government official who commented that the main reason DPOs are in financial trouble is "because they don't sell anything".

This simple statement reveals a lot about government ambitions for the third sector and suggests that moves towards financial self-sufficiency via service provision will be encouraged.

But, as Chapter 2 illustrates, many DPOs have little experience or expertise in business development or social enterprise. Most DPOs were not set up to deliver services on a commercial scale and they find it hard to compete with larger private and third sector providers who have more resources and tendering expertise as well as the ability to reduce costs through economies of scale. Those DPOs that are most successful in winning service contracts seem to be those that were set up exclusively for the purpose. Organisations like Breakthrough, a relatively large DPO and a successful provider of employment services to disabled people, employs 70% disabled people and is run as a successful social enterprise.[30]

Organisations like Breakthrough demonstrate that it's possible to be a DPO, win contracts and make a surplus, but for those DPOs that began life as local peer-support networks or rights campaigners, moving into service provision is not easy, nor necessarily desirable. Most business advisers would shake their heads at the idea of a women's rights campaigning group deciding to branch out into providing breast cancer screening services, but DPOs attempt this kind of leap all the time.

[29] http://www.cabinetoffice.gov.uk/third_sector/third_sector_review/Third_sector_review_final_report.aspx
[30] http://www.breakthrough-uk.com

C28897 Disability LIB Report 2/4/08 13:03 Page 33

DPOs' traditional role as campaigning organisations can also sit uneasily with their role as service providers. The strength of DPOs comes from their approach to highlighting the barriers disabled people face in accessing equal rights and finding innovative solutions to overcome them. However, many local authorities don't like employing service providers that also highlight poor local practice, campaign for improvements in services and advocate for individuals' rights and entitlements. It is clearly possible to be both campaigner and service provider but further guidance on how to balance these two roles would be of benefit to both DPOs and service commissioners.

It is worth examining the reasons behind some DPOs' decisions to tender for service contracts. Funding is an obvious one. Profit-making services provide additional income to support other, less fundable work, like peer support or campaigning. Given that DPOs now have to compete with thousands of other third sector organisations for funding, moving into service provision can sometimes seem like the only way to survive. However, there are other, arguably more important, motivations than just funding.

For disabled people, the realities of impairment mean that getting the right support services is key to being able to exercise choice and control over their day-to-day lives and to being an equal citizen. Consequently, the need to provide practical services such as direct payments support, advocacy and skills training is greater for DPOs than for other groups. Indeed, many DPOs that started life as peer-support, advocacy and campaigning organisations have moved into more formal service provision to plug the gaps in the social care system for those who are ineligible for statutory services.

As the welfare state is gradually replaced by the facilitating state, state support for disabled people has reduced. Private and voluntary sector organisations are increasingly getting involved in the delivery of a range of social, health, education and leisure services traditionally provided directly by the state. Support for greater devolvement of decision-making and choice for disabled people over the services they use is creating a new landscape where disabled people are increasingly viewed as customers with power, rather than people with problems. This creates opportunities for DPOs, which have been some of the fiercest critics of one-size-fits-all, impersonal, state-designed services for disabled people, to get directly involved in developing and delivering services that disabled people want and that embody the principles of independence and choice.

The fact that DPO campaigning was instrumental in bringing about some of the key changes in legislation and policy to make independent living possible also means that DPOs see providing some services as their natural territory. There is a commonly expressed view within the Disabled People's Movement

that organisations owned and run by non-disabled people do not have the ethos or understanding to run services that genuinely empower disabled people. And that therefore, where DPOs exist, they should be preferred service providers. These feelings of ownership mean that when contracts for direct payment support services or advocacy services are awarded to non-DPOs there is an understandable sense of injustice.

DPOs often express frustration and anger that service commissioners don't appreciate the additional value that DPOs bring to providing services. DPOs exist purely for the empowerment of disabled people; unlike some other providers, they don't provide services just because there's profit in it. The 'Nothing about us without us' principle underpins the DPO approach to service provision. Because they are run by disabled people DPOs provide services that reflect and respect what disabled people themselves want. That commissioners don't appreciate this crucial difference in ethos is understandably difficult to swallow, especially as many services, like independent advocacy and direct payments support, were conceived by the Disabled People's Movement with the express aim of empowering disabled people.

However, commissioners are motivated by value for money and with a limited appreciation of the added value of rights-based empowerment they tend to select the provider who can do what they need cheapest. Getting this added value understood at a commissioning level is a huge challenge for DPOs, especially as many non-DPOs are getting good at talking the language of rights and empowerment.

The role of women's groups in establishing services for women who experience domestic violence provides an interesting parallel. Women's refuges were set up in response to the dearth of support for women experiencing, or at risk of, domestic violence. They were a core vehicle for tackling one of the most pernicious manifestations of women's inequality and oppression. Fundamental to these services was the fact that they were run by women for women. However, women's groups, like many DPOs, now find themselves having to defend the right of user-led organisations to run the services that they originally invented. Increasingly, women's refuges are being set up and run by housing associations with no links to the women's movement at all.

That said, lack of understanding on the part of commissioners is not the only reason DPOs are losing out on contracts. As we saw in Chapter 2 some DPOs are often too resource and time poor to be able to submit competitive tenders or to deliver on them if they win. Financial insecurity, small numbers of paid staff and higher staff turnover as well as the prohibitive cost of employing dedicated IT, human resources and other specialist staff means it is hard for DPOs to demonstrate that they have in place the increasingly stringent policies,

C28897 Disability LIB Report 2/4/08 13:03 Page 35

procedures and infrastructure necessary to win contracts. These insecurities understandably make commissioners nervous. There is considerable risk for commissioners associated with awarding contracts to unstable organisations, but without them it is hard to see how DPOs can hope to become more stable.

The narrow geographical focus of many DPOs can also make it difficult for them to compete. Many local authorities tender for services across a local authority area, which excludes local DPOs who do not have the necessary reach. Recently in Kent a local DPO could not tender for a service they were well able to provide because the local authority wanted one contractor to provide the service county-wide. If this DPO had been able to join forces with other DPOs able to provide similar services in other parts of Kent they could have submitted a tender.

Smaller community of interest DPOs such as BME groups or mental health groups face similar problems. While they may have the necessary expertise, their focus is often considered to be too specific to be a real contender for contracts. Instead, commissioners prefer to give work to 'for' organisations that can bid for contracts area by area, and provide a uniform service.

The flip-side of this narrow focus is that DPOs overstretch themselves in order to win regional contracts which they then don't have the capacity to deliver. An example this is Choices, which went bankrupt after taking on service contracts across the whole of southern England.

DPOs that have a very specific focus, for example local access groups, often find it difficult to sell their services commercially. Many access groups have a considerable amount of expertise around access to the built environment, and in some cases of conducting access audits, but mostly operate as volunteer groups with minimal funding. Individuals have a lot of practical knowledge but they are rarely qualified access auditors, so are not in a position to tender for access audits for local statutory or private organisations. As a result contracts tend to go to non-disabled consultants. It would be much more cost-effective in the long run for local authorities to support access groups to acquire the necessary qualifications and professionalism than to pay for one-off consultants who often make mistakes because of lack of local knowledge or skills to engage with disabled people.

It is also important to recognise that DPOs don't have an automatic monopoly on best practice in service provision – there are poor performing DPOs just as there are poor performers in every sector. This needs to be understood by DPOs, who sometimes behave as though they have an automatic right to be awarded contracts just because they are a DPO. In the current climate of value for money, arguments for resources based on political entitlement no longer hold

any weight, so DPOs will have to prove themselves on an equal footing with competitor organisations.

Finally, a note of caution. The extent to which DPOs embrace service provision still needs careful consideration. 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. It is not obvious that becoming a formal service provider, as opposed to providing informal peer support, is the right solution for many DPOs. 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 risk losing valuable focus.

The potential for DPOs to be involved in designing rather than delivering services also needs much closer consideration. The UK has a poor record on commissioning services; we tend to buy services rather than commission them. DPOs could play a significant role in helping to establish a genuine commissioning process, based on the views and needs of individual disabled people. This is arguably where DPOs can be of most value and could have greatest impact on the equality agenda.

2. Formal co-operation to achieve long-term stability

Internecine 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.

So far in the paper we have talked about DPOs as a 'sector' but perhaps this isn't very accurate. There is an argument to say that DPOs are a collection of individual organisations, thriving or surviving independently of each other, though linked by common cause. Umbrella bodies like UKDPC provide valuable information and resources to their DPO members and determine the focus for national campaigning but traditionally their focus has not been on promoting the business interests of DPOs. There is no DPO 'trade' body whose role is to facilitate formal co-operation and joint working between organisations or engage in sector-wide negotiations, for example for standardised charges for particular services.

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. DPOs fighting for survival would be sensible to assume that no-one is coming to their rescue and recognise that the only people who really care about the survival of DPOs are DPOs themselves.

Consequently the onus must be on DPOs 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, many of which are more comfortable with arm's length relationships. 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.

The Disability LIB alliance demonstrates what can be achieved when DPOs come together to think strategically about the needs of the whole sector. Their role in supporting DPOs to identify their priorities for development, explore partnership opportunities and convince them of the value of a more joined-up approach will be critical. This is already happening in places at a local level but more leadership and support to do this everywhere is certainly needed.

Disability LIB must also consider how the sector can effectively support the full diversity of activities that DPOs offer while remaining financially sustainable. How to retain core aspects of DPO culture like creativity, diversity, democracy, rights campaigning and peer support in the face of pressure to become more corporate and service-focused will be a key challenge.

Formal co-operation on this level will also enable the DPO sector to influence government-funded capacity-building mechanisms like Change Up and Capacity-builders. To date, DPOs have missed out on mainstream capacity-building support because what was available did not take the specific needs and situation of DPOs into account. A more united and focused DPO sector would be able to exert far greater influence over these programmes to ensure DPOs benefited equally from Government investment in the third sector.

3. 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. Many disabled people, not just the young, have mainstream jobs and non-disabled friends and don't relate to concepts of oppression or disablism or the need for organisations purely for disabled people. 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.

It's worth reflecting for a moment on the fact that there are few mainstream, well-known disabled figures who are considered standard bearers for disabled people's rights. The struggle for equal rights for disabled people does not feature in the modern history curriculum nor is there a disability equivalent of the 'I have a dream' speech. Where feminism can point to the suffragettes, Germaine Greer and Mary Wollstonecraft, gay rights to Oscar Wilde and the Stonewall rioters, and black rights to Martin Luther King, Malcolm X and Nelson Mandela, disabled people don't have a famous figurehead who embodies the struggle for disability rights.

As a result, young disabled people don't have a sense of the history of the struggle for disability rights (or their part in it), which makes the Disabled People's Movement seem of little relevance. In some ways DPOs are also victims of their own success. A Scope poll suggested that non-disabled pop stars and footballers are more likely to be role models for young disabled people.[31] DPOs report that when they do give young disabled people opportunities to engage with the issues they care about they are incredibly active and passionate. Finding out what young disabled people want from DPOs is therefore key to recruiting the next generation of leaders.

Reaching out to groups of disabled people who would not traditionally consider themselves to be DPOs is also a vital part of developing the sector. There are a number of diverse organisations of disabled people that are not included in formal directories of DPOs but that are run by disabled people to further their rights and equality. Encouraging these groups of disabled people to link in more formally to the Disabled People's Movement is crucial if DPOs are to attract new blood and ensure their on-going relevance.

Finding ways to attract disabled people with the relevant skills to work for DPOs is also a challenge. DPOs highlight lack of skills and experience as a key barrier to achieving stability and growth so developing mechanisms for attracting qualified professional disabled people into the DPO sector is crucial.

To ensure DPOs continued existence it is essential that DPOs establish their relevance with a broader cross-section of disabled people, including younger people, those living in institutions, those from BME and LGBT communities as well as those who do not see disability as a rights issue. An ageing population could provide a new cohort of disability rights activists if DPOs can find ways to engage them effectively. DPOs should also focus their attention on attracting professionally qualified disabled people who want to use their skills to benefit DPOs and disabled people's equality or would just like to work with other disabled people.

[31] Scope Press and PR survey – I want to be a Spice Girl! (2002).

C28897 Disability LIB Report 2/4/08 13:03 Page 39

Like all movements for equality, the Disabled People's Movement has faced challenges in its efforts to include disabled people from across the UK's diverse communities. The most successful 'umbrella' DPOs are those that work across impairments, communities and age groups, employ a diverse workforce, work in partnership with community specific DPOs, and are in touch with the communities they serve.

But other DPOs still struggle to be inclusive. Specific communities of interest organisations of LGBT or BME disabled people (including Equalities National Council) have developed at national and local level because of the shared identities of those communities, but also because of the failure of 'mainstream' DPOs and LGBT and BME organisations to include them. Many of these groups struggle to find funding and to be heard. Yet they are an essential part of the DPO network and potentially a resource for the whole movement.

4. Tackling Disablism within the Third Sector

The impact of disablist policies, attitudes and institutions is well-documented in society at large. What is not so well-documented or analysed is the level of exclusion experienced by organisations of disabled people from the traditional charity or third sector, including the intermediary or co-ordinating organisations.
Anne Pridmore, disability activist, consultant, Scope Trustee and a former board member of NCVO, is well aware of the barriers disabled people face in the mainstream voluntary and community sector. Her experience has shown that there is a stark lack of genuine interest in disability issues and diversity more generally. This includes major issues like diversity being seen as unnecessary, or it being deemed acceptable that disabled people can be represented by non-disabled people, even though this would be unacceptable for other groups. In addition, the mainstream providers' approach to such things as paying people for attendance at meetings, making sure meetings and meal breaks are accessible and that travel arrangements meet the needs of disabled members is far from satisfactory.

The co-ordinating organisations for the third sector exist to provide services and support and to represent their members. Most activities organised by the third sector are still inaccessible to DPO representatives often as a result of simple access barriers like failure to provide information in alternative formats or a physically accessible meeting room.

This assumption is mirrored by debates around provision of information in languages other than English. Most people involved in the third sector recognise the importance of providing information in alternative languages for non-English speakers but they don't expect the representatives of these organisations to need the meeting documents translated. Because there are so few disabled people involved in

C28897 Disability LIB Report 2/4/08 13:03 Page 40

the third sector (and those that are tend to adapt to the disablist environment because they feel unable to challenge it) the sector has never had to address accessibility issues seriously. This creates a vicious circle of exclusion – DPO representatives don't get their needs met, so they don't participate, so they don't get their needs met.

Government and funders have also failed to recognise this exclusion and have not used policy or funding levers to initiate the necessary change. The third sector has demonstrably failed to embrace disability as a human rights and equality issue. Third sector co-ordinating, training and capacity-building organisations have also failed to address disablism in their staffing, organisational systems, governance structures and services. It has not critically evaluated its past and embarked on a process of reform around disability in the same way it has for gender and race and to some extent sexual orientation. If this examination and change agenda does not take place then the third sector will continue to be a lightning conductor for all the prejudices and oppressive practices that disabled people face in wider society.

Many third sector organisations, and funders, still equate disability with social care. This narrow interpretation of disability often leads to DPOs being excluded from mainstream third sector activities. Where disability organisations are included the third sector continues to view carers' organisations, organisations 'for' disabled people and service providers, as the 'experts' on disability, rather than disabled people themselves. Despite the DDA 2005 Duty to Promote Disabled People's Equality, DPOs are not encouraged to be involved in Local Compacts, Local Strategic Partnerships and other initiatives involving the voluntary sector, consequently, they do not benefit from funding or support.

The effect of this exclusion is that the DPO sector has not benefited from third sector support and capacity-building, which explains many of the difficulties they face. However, it is also important to recognise that while this exclusion persists, third sector organisations and their co-ordinating bodies are not benefiting from the extensive expertise, experience and insight contained within the DPO sector.

It is clear that a dialogue between DPOs and third sector co-ordinating 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. This is one of the main reasons why Disability LIB will be working with NCVO to establish links with the mainstream capacity-building sector.

C28897 Disability LIB Report 2/4/08 13:03 Page 41

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 them 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.

Six DPOs have come together, with Scope as an ally, and Pilotlight and Emason as preferred suppliers, to develop a set of interventions to alleviate the crisis facing DPOs and help the sector grow in its capacity and reach. This unique partnership, led and controlled by disabled people will examine the current status of DPOs, their role and development opportunities. Their approach to capacity-building the DPO sector is laid out below:

Disability LIB alliance

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 numbers 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, 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.

The models outlined below are not intended to be prescriptive – far from it. It goes without saying that disabled people must take the lead position in any model selected and work with the third sector as allies, not beneficiaries. However, they are intended to provide some ideas for ways DPOs might reorganise themselves as a sector to help individual organisations fulfil their potential in the most efficient and cost-effective way. The role of existing umbrella DPOs, such as NCIL, UKDPC and national People First, will be crucial in leading discussions within the sector

on the value of these models and the best way to implement any new approach.

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 focus of the models described below is meeting the needs of DPOs as organisations, rather than the needs of the disabled people they exist to serve. We feel that this is a useful distinction.

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.

As many co-operatives have a business base this model could support an increase in the number of DPOs providing profitable services. The profits which could then be distributed back to member organisations to fund other less fundable social impact work.

A variation of this might be a national organisation with local affiliated groups. They may be separate organisations together forming a federal structure or may legally all be part of one organisation with a branch structure. Existing examples of this type of model include Friends of the Earth, MIND, Relate, Victim Support and the Neurological Alliance.

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.

The alliance would be defined via a formal contractual relationship and would preserve the independence and integrity of each party. The non-DPO might provide direct funding or donations in kind such as office space, human resources or IT expertise or advice on working with the media. In exchange they would receive access to something the DPO could offer. This could be advice on how to improve access, opportunities, how to consult with DPO members or to end-user test new products, such as mobile phones or disability equality training. Whatever the details of the specific contract, the result would be that each party would get something they needed from the relationship without compromising their independence.

C28897 Disability LIB Report 2/4/08 13:03 Page 44

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.

Some DPOs might feel uncomfortable about this because it feels like a charity model. There is a risk if not properly set up that this model could be rather disempowering and patronising. However, approached on the basis of a fair exchange of goods or services, it could be a very effective means of giving DPOs the stability they need to develop.

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. Support with legal queries, putting funding bids and tenders together, business planning and strategy, policy development and campaigns strategy could all be provided through a national service model, potentially with regional sub-offices. This type of model would also be able to promote partnership, working across DPOs together where appropriate. For example, bringing together three or four smaller DPOs to submit a joint tender for work across a local authority that they could not do alone.

It could also work by sharing staff skills. For example, where one organisation has an advocate with in-depth skills on social care and another has an advocate with knowledge of housing issues, they could work together and share some case work, and also train each other up.

This differs from the Change Up Hub Model, detailed below, in its focus on providing practical support rather than advice. The Sharing Services model on a large scale could provide essential practical support at a significantly lower cost per organisation than is currently available and at the same time provide employment opportunities for disabled people with professional qualifications and skills.

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

C28897 Disability LIB Report 2/4/08 13:03 Page 45

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 becomes apparent. The cost of such an enterprise would be very low when shared across the thousands of DPOs in the UK and would probably pay for itself in new services and influence.

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. This model lends itself to organisations set up exclusively for this purpose or organisations that wish to establish a separate profit-making arm. Depending on the structure of the organisation profits would be used to fund less fundable activities like rights campaigning, self and peer advocacy or advice services or to fund the activities of other DPOs. (Linked to Co-operative model above.)

Such a system is called cross-fertilisation and is commonly used as a way to fund unprofitable activities. For example, bus companies are often required to run a profitable route along with an unprofitable one and use the profits from one to subsidise the other. A more relevant example would be an organisation that sets up a social care agency as a social enterprise (maybe with other partners) with any profits potentially being put back into the DPO.

Enterprise groups might also be set up around mutual interests. These may be geographical, impairment-specific, skills-based or issue-based. This model also comes nearest to fitting in with the contracting regime envisaged by the government. This model could be used to create a base for selling services, from social care, payroll, training for social care staff and direct payments support, to training, consultancy and access audits.

Existing Models – The Hub Model

This model is based on the project set up by the National Council for Voluntary Organisations (NCVO). It is based on a group of six national partnerships called national hubs that offer free services, information and support on six topic areas. All six partners are charities and voluntary organisations.

Each hub is a partnership that combines the expertise and knowledge of a range of support agencies. They aim to offer the best available national support on each topic. The hubs are funded through a ten-year government initiative called Change Up,[32] which is

[32] www.changeup.org.uk

C28897 Disability LIB Report 2/4/08 13:03 Page 46

administered by Capacity Builders.[33] This aims to increase the quality and quantity of advice and support that is available to voluntary and community organisations, which includes charities, community groups and social enterprises. The six topic areas are:

- getting funding
- finding, keeping and managing volunteers
- managing and developing staff
- understanding your purpose and tracking your achievements
- making good decisions and having good senior staff and trustees
- making good use of computers and other information technologies.

Traditionally, DPOs have not found it easy to take advantage of mainstream capacity-building services and resources. However, there are opportunities for DPOs (if suitability funded) to influence and enhance the Hub model by helping to make it fully inclusive of disabled people. This could enable them to provide advice and support that reflects the challenges DPOs face, especially in relation to the specific needs of recruiting and supporting disabled staff and volunteers and meeting people's technology and access needs.

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.

[33] www.capacitybuilders.org.uk

C28897 Disability LIB Report 2/4/08 13:03 Page 47

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

C28897 Disability LIB Report 2/4/08 13:03 Page 48

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.

C28897 Disability LIB Report 2/4/08 13:03 Page 49

Appendix A

The Disability LIB (Listen, Include, Build) alliance consists of:

The Alliance for Inclusive Education
Disability Awareness in Action
Equalities National Council
People First
Preston DISC
Scope
The UK Disabled People's Council

The Big Lottery Fund's **BASIS programme** has awarded the Disability LIB alliance a grant of £4,245,382 to fund the three-year Disability LIB project.

The project will establish the UK's first disability-led alliance that will work with 200 DPOs in England to enable them to become more effective through a range of support, such as information, advice and training, provided by Scope and its six partners – Alliance for Inclusive Education, Disability Awareness in Action, Equalities National Council, People First and Preston DISC and United Kingdom Disabled People's Council.

Appendix B

Disability LIB alliance Stage One Research

The Disability LIB alliance was awarded a three month development grant of £212,000 as part of the BASIS Stage 1 grant. The findings of this research are detailed in Chapter 2 of this document,

Research Methodology

Six Development Workers, supported by two Research Consultants, were employed to conduct research into the capacity-building needs of regional and sub-regional Disabled People's Organisations in England. 384 DPOs were contacted, of whom 226 were meaningfully consulted using a combination of face-to-face meetings, written questionnaires, focus groups and regional seminars in North West England, the West of England, London, and South Yorkshire.

Researchers also evaluated best practice models created through mainstream capacity-building initiatives including ChangeUp, Consortia, the National Centre for Voluntary Organisation (NCVO), and National Association of Voluntary and Community Associations (NAVCA) were researched.

C28897 Disability LIB Report 2/4/08 13:03 Page 50

Bibliography –

A selection of the key texts that have directly or indirectly informed the report

Barnes C (1991) Disabled People in Britain and Discrimination: a case for anti-discrimination legislation London: Hurst and Company

Barnes C & Oliver M (1995) Disability Rights: rhetoric and reality in the UK Disability & Society Vol. 10 No 1 pp 111-116

Campbell J & Oliver M (1996) Disability Politics: understanding our past, changing our future London: Routledge

Humphries S and Gordon P (1992) Out of Sight Plymouth: Northcote

Maynard-Campbell S et al (2007) Mapping the Capacity and Potential for User-Led Organisations in England: A Summary of the Main Findings from a National Research Study commissioned by the Department of Health London: Department of Health

Mason M (1990) Internalized Oppression in Disability Equality in Education, Reiser R and Mason M (eds) London: ILEA

Miller P and Parker S (2004) Disablism: How to tackle the last prejudice London: Demos

Oliver M (1984) The Politics of Disability Critical Social Policy Vol. 11 pp 21-32

Oliver M (1990) Critical Texts in Social Work and the Welfare State. The Politics of Disablement London: Macmillan Press Ltd

Oliver M (1993) Disabling Barriers – Enabling Environments Swain J et al (eds) London: Sage

Oliver M (1996) Understanding Disability: from theory to practice Chatham: Mackays

Priestley M (1999) Disability Politics and Community Care London: Jessica Kingsley Publishers

C28897 Disability LIB Report 2/4/08 13:03 Page 51

Notes

C28897 Disability LIB Report 2/4/08 13:03 Page 52

Notes

C28897 Disability LIB Report 2/4/08 13:03 Page 53