



Disability

Listen Include Build



**Interim Report
March 2010**

**'Disability isn't about being brave, it's about being organised'
Ian Dury, Rock Singer / Songwriter 1942 – 2000**

Introduction

This report provides a brief interim report on the Disability LIB project. It gives some background to the project, gives details of DPOs in England, an overview of our activities in the last eighteen months and some analysis of future trends. Should you require further details or alternative formats please contact us at the details at the end of this document.

What is Disability LIB?

Disability LIB is a capacity building project for Disabled People's Organisations (DPO's) in England. We are an alliance six DPO's, Disability Awareness in Action, Disability Equality North West, Alliance for Inclusive Education, Equalities National Council, People First, United Kingdom Disabled People's Council and one Disability Organisation, Scope.

Our mission is to support DPO's in the voluntary and community sector to be informed, efficient and influential. We promote DPO issues and work to ensure that they have access to infrastructure support. We provide support and advice on key capacity building issues, such as management, governance, business skills, networking, inclusion and leadership.

Disability LIB came out of the research report 'Thriving or Surviving: Challenges and Opportunities for Disabled People's Organisations in the 21st Century'. The research highlighted infrastructure and capacity building issues for DPOs and how they are disadvantaged across a range of areas. This includes sustainable funding, the costs of access, commissioning & competitive tendering, skills shortages, management, governance & leadership.



'Cabbages of the world, unite!'

Ed Roberts,
Disability Rights Activist
1939 - 1995

Disabled Peoples Organisations: Who, where and what are they?

Our work is focused solely on capacity building Disabled Peoples Organisations in England. Our definition of a DPO is a community group, run and controlled by disabled people. They are unique in that they create the opportunity for disabled people to voice and define their experiences. They are committed to promoting inclusive and independent living and challenging human rights abuses and disability discrimination. DPOs are involved in providing a range of activities and services. They range in income, size, activities, areas they cover and other characteristics.

As part of our work we have been mapping DPOs across England, capturing details of size, activities and other characteristics. This we believe is crucial to supporting DPOs in the future. We have identified over 400 DPOs in England that are currently active and are continually updating this information. By maintaining and understanding trends and issues affecting DPOs we believe we will be able to support them to be best equipped to face future challenges and remain relevant to their purpose and value.

Using Government Office regions and based on DISLIB contact with approx 400

known DPOs the following table gives a breakdown of where DPOs are located in England.

Region	DPO %
East Midlands	6%
East of England	6%
London	32%
North East	3%
North West	16%
South East	9%
South West	10%
West Midlands	13%
Yorkshire	7%

The regional variation can be linked to population statistics, although certain areas may require targeted capacity building initiatives. The area with the smallest number is the North East with 3% of DPOs, this has the lowest population [2.5mil], the highest number of people of working age claiming social security benefit [18%] and 2nd smallest area of sq km [8.5k]. London has the most, with 32% of DPOs, the highest population [7.6mil], with 13% of people of working age claiming social security benefit [13%] and the smallest area of sq km [1.5K].

There is also huge difference in DPO income and activity. The following paragraphs group DPOs primarily in terms of income as unfunded, small, medium, large and national. However, while this is useful to understand a DPO sector, it should be noted that there is huge diversity and variety within it and so there are many other ways to characterise them. Also, there are many other issues

that we do not have any reliable data about, such as the number of disabled people employed in DPOs.

Unfunded – self help groups, informal networks, special interest projects, single issue campaigns and coalitions. These are usually very small and themed around specific issues and provide a particular, sometimes one off function, for example impairment specific self help or single issue campaigns. They are likely to be run voluntarily or with the support of a host organisation, are unincorporated with no formal or legal status, and may not have formal policies and procedures.

Small – up to £15,000 per annum, access groups, self-advocacy networks. Small campaigning groups 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. They may have a local area or a community themed focus, i.e. Bengali visually impaired people in Tower Hamlets, East London.

Medium – £20k to £150k, small information, advice and advocacy community based projects. Medium-sized campaigning, advocacy and self-advocacy organisations with one worker or small teams of paid staff, charity status, and links into national and local networks. They may have service delivery contracts with local authorities for direct payment services, employment support, information or advocacy.

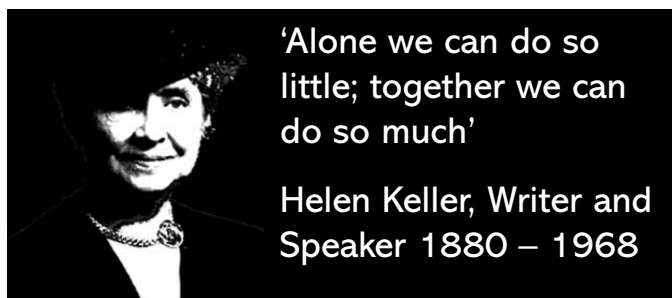
Large – £150k to £2million, regional organisations providing range of independent living services. This group has the smallest number, but has the

greatest income, will have a regional focus, promote the philosophy of independent living and deliver related services. They will be engaged in national policy consultation, capacity building of other DPOs and will innovate new services and initiatives. They are likely also to increase their annual income through service delivery opportunities that arise from personalisation.

National – income dependent on activity, around £100k – £200k.

These are established, national DPOs whose function is to lobby and act as a national voice for their membership, as well as providing policy analysis, networking and capacity-building to their member groups. These groups face difficulties with long term, sustainable funding, and have capacity-building and infrastructure issues of their own.

These DPO income categories bear no comparison with traditional disability charities that have levels of annual income often in excess of £100 million. Additionally, the size of the health, social care, independent living, disability equality and related industries is huge. For example in 2007 there were an estimated 35 thousand third sector organisations providing health and social care related services. In 2006 the total funding for these services was £12bn. Again this is a sizable amount compared to the UK government's £87bn budget for health and social care in 05/06.



'Alone we can do so little; together we can do so much'

Helen Keller, Writer and Speaker 1880 – 1968

So what have we done so far?

Disability LIB is a Big Lottery Fund project from June 2008 until July 2011. In the first eighteen months significant progress has been made against the project plan and outcomes. We have provided capacity building work with 91 DPOs, and have received positive feedback. We have worked with existing and new groups with a range of incomes, covering a range of issues and support needs.

We use a tailored approach in our work and develop DPO specific work plans based on their requests and assessment of capacity building needs. Through this, we have provided advice and support to numerous DPOs around governance, project planning, facilitating team away days, providing mentoring support, offering conflict resolution, finance and budgeting and advising on managerial issues.

Specific examples of this tailored support include our work with the following DPOs;

Camden People First – helped draft an accessible project plan that enabled them to secure a 3 year contract with the local authority.

Lancashire Centre for Independent Living – provided governance advice for the board, developed a fundraising

strategy and mentoring support to form a user led consortium in Lancashire.

Disability Cornwall – facilitated a strategic analysis and future planning session with staff and trustee team to be incorporated in their business plan.

In addition to the tailored support, we have led a number of other activities and events. These have offered targeted support around particular issues. Examples of this are as follows.

Young Disabled Persons Leadership – ALLFIE conducted research about young disabled peoples leadership and are running three pilot projects with DPOs to develop their capacity to work smarter with young disabled people. This work shows potential for DPOs to explore additional work areas and access income streams, that might include running apprenticeship schemes, youth projects, leadership courses, etc.

BME Ambassadors – ENC is running a leadership development programme focused at disabled people in BME community groups, reviewing how inclusive DPOs are to them.

DPO Leadership – working with Essex Coalition of Disabled People we delivered three workshops focusing on developing leadership of disabled people in DPOs.

Income Generation – UKDPC facilitated a number of training sessions on fundraising from trusts, and how to create winning bids and Tender effectively.

Networking activity – UKDPC has run a series of regional network building events. At these events DPOs have the opportunity to share skills, resources and experiences in relation to a range of

issues including governance, bidding for Local Authority contracts, and sharing experiences in the current national DPO climate.

Human rights and DPOs – DAA ran intensive training sessions for DPOs to build up knowledge around human rights legislation and how to make use of it in their work.

DPOs and people with learning difficulties - People First is carrying out access audits focused on the inclusion of people with learning difficulties in DPOs.

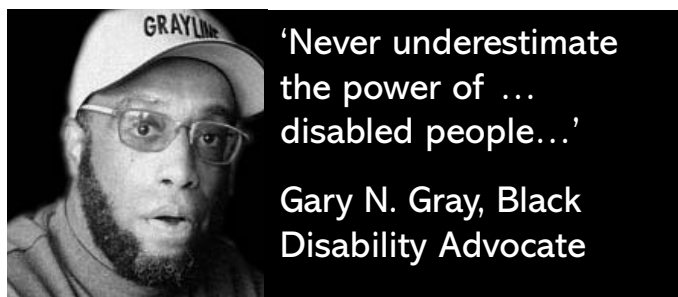
Information – we produce two monthly e-updates to DPOs. The first contains news and issues relevant to DPOs, such as fundraising, training and other opportunities. The second, produced by DAA gives up to date information about Human Rights and the UN convention.

Business Coaching - Through our partner organisation Pilotlight, we offer a uniquely managed capacity-building process that supports organisations in exploring their vision and giving them the skills to create strategic plans to develop sustainable organisations. To date we are working with 6 DPOs in this way.

Through our engagement with DPOs we have built up detailed knowledge of capacity building needs and issues facing DPOs. Increasingly we are being asked to support existing groups to develop consortia or partnerships and are developing tools to do this effectively. A consistent theme we notice across a large number of the groups we engage with are tensions between 'governance and management' structures. Often DPO managers will report that they do not have appropriate support from their trustees, while trustees report that they are

not involved in decision making processes, or are not given information necessary to complete their roles.

Additionally, many DPOs state they have become too funding led, rather than mission led, they do not have current project plans and are missing out on development opportunities as a result. This and other learning is being collated and will be used to inform our future activities and sources of funding.



The future

As a result of the changing UK 'social care' and 'disability equality' political landscape, in terms of the move toward 'user involvement and user led services', the DPO sector is likely to experience significant growth in future years. There is a wealth of social change initiatives and reform, such as the personalisation agenda and recommendation 4.3 of the Government's Improving Life Chances of Disabled People report that calls for a Centre for Independent Living in every Local Authority area.

We welcome this focus, as issues that affect sustainability and effectiveness of DPOs include a supportive environment within the locality which can lead to the securing of funding streams, as well as a business focused approach.

(Maynard-Campbell, A. 2007, Mapping the Capacity and Potential for User Led Organisations in England). Generally, Local Authorities are positive about 3rd sector organisations and the high quality, responsiveness and good value for money they offer. (DOH 'Third Sector Market Mapping' Feb 2007).

However, while we acknowledge that there is a current supportive policy agenda for DPOs, we also recognise that the future is uncertain. Both the economic downturn and public service reform are likely to have major impacts on DPOs and are likely to reduce and change income streams significantly. With that said, DPOs occupy a unique space within the voluntary sector and are necessary partners in the Government's fulfilment of the Independent Living Strategy and related initiatives. Understanding this, and taking every opportunity to promote DPOs as key to the inclusion and equality of disabled people is a priority to support DPOs future development.

As well as continuing to offer DPO capacity building support over the next eighteen months, we are also working on a project to look at a future strategy for DPOs, examining what issues lie ahead and how to respond to them. We are working in partnership with NCVO's 3rd Sector Foresight project www.3s4.org.uk. This project will carry out some 'strategic analysis' to look at social, political and other external 'drivers' or 'trends' that will impact on DPOs. This will help ensure that DPOs are aware of the 'trends' that will affect them, such as changes to government, policy, the climate, economy and other issues. Once complete we will promote this and work with DPOs to create sustainable futures.

Further information

If you want more information, or to access the support available please contact us. We are happy to come out and give a presentation, discuss capacity building support and how we might be able to work together.

Please also pass this on to anyone you may think would be interested. We are also keen to make links and network with individuals and organisations involved in related issues so please do make contact with us.

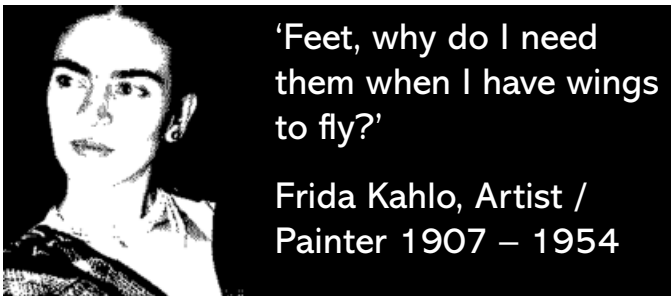
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'Feet, why do I need them when I have wings to fly?'

Frida Kahlo, Artist /
Painter 1907 – 1954