



Disability

Listen Include Build



**‘Less courses,
more conversations’**

**Disabled Peoples Organisations
(DPOs) and Mainstream
Capacity Building**

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

Frida Kahlo,

Artist / Painter 1907 – 1954



November 2010.

This position paper came out of the information presented and issues discussed at a roundtable event organised by Disability LIB, held at NCVO on 22/09/10 and attended by representatives from the following organisations. ACEVO, Black Training & Enterprise Group, Capacity Builders, Council of Disabled People Warwickshire & Coventry, DIAL UK, Disability Action in Islington, Disability Equality North West, Equality National Council, Liverpool Charity and Voluntary Services, National Equalities Partnership, NCIL, NCVO, Norfolk Coalition of Disabled People, Office for Civil Society, People First, Pilotlight, The Vassal Centre Bristol, UKDPC and the Women's Resource Centre.

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'Less courses, more conversations'

Disabled Peoples Organisations (DPOs) and Mainstream Capacity Building

A simple line drawing of a person with dark hair, wearing a grey long-sleeved shirt and dark trousers, standing and gesturing with their hands. A speech bubble above their head contains the text: "Yes but we don't always know how to do it".

Yes but we don't
always know
how to do it

Summary

This is a position paper about Disabled Peoples Organisations (DPOs) and mainstream capacity building. It came out of a roundtable event held on 22/09/10 involving a range of DPOs and mainstream capacity builders. The event explored challenges and opportunities for DPOs and mainstream capacity building organisations alike when working together, and the benefits for them to do so. Using information presented at the event, the paper first outlines the purpose of capacity building and some of the characteristics of Disabled Peoples Organisations, including income, activities, added value and position within the Disability sector. The priorities and actions for DPOs and mainstream capacity building organisations to work together identified by participants at the roundtable event are then presented. These included:

- Developing methods to capture added value of DPOs;
- Increasing the profile, understanding and research data of DPOs as emerging subsector;
- Developing the profile, and use of mainstream capacity building programmes by DPOs.

If undertaken these actions will not only help forge useful relationship between DPOs and mainstream capacity builders, but also how the wider third sector can become more inclusive of disabled people in all of its activities, services, and as progressive employers and ethical organisations.

Contents

Crucial Issues	4
Capacity Building	4
Disabled Peoples Organisations (DPOs)	6
Added Value	7
Disability Equality North West	8
Geography	8
Table 1. DPOs by English Region	9
Income	10
Figure 2. 2009 Income in Millions of	8
Disability Charities & 100 DPOs.	11
Mainstream Capacity Building and DPOs.	11
What are the capacity building needs of DPOs?	12
How can mainstream Capacity Building organisations engage with DPOs?	13
Priorities, Implications & Actions	15
Conclusion	16
References	16
Notes	17

Less courses,
more
conversation

Note:

Yes, we know “less courses” is ungrammatical, but it’s a verbatim quotation during a passionate debate, and in those circumstances grammar is frequently the first casualty.



'Less courses, more conversations'

Disabled Peoples Organisations (DPOs) and Mainstream Capacity Building

Crucial Issues

'Unsurprisingly the major issue for the whole of the third sector is uncertainty because of the forthcoming biggest reduction in public spending for as long as most of us can remember. The recent comprehensive spending review proposes unprecedented reduction in state run public services. This will result in big cutbacks in funding whether this is direct from government departments or from agencies and local authorities. NCVO's work on 'crowdsourcing the cuts' highlights examples of big cuts in funding from local authorities (see <http://www.ncvo-vol.org.uk/>).

Anecdotally, it is also clear that in spite of assurances around ring fenced spending areas, like health and aspects of social care, they are under the same pressure to reduce spending or be more efficient. Some organisations may indeed benefit from the increased outsourcing of public services. This however will favour larger organisations delivering services, because they will be better equipped to adapt and develop contracting and bidding skills. But those smaller organisations, who do campaigning and advocacy activities are not likely to benefit.

The impact on Disabled Peoples Organisations will be severe and will affect local, regional, national and special interest

groups alike. Also, it is not clear how infrastructure initiatives will be supported in the future and the Office for Civil Society are currently running a review of infrastructure. The coalition government hints that it may encourage bursaries, collaboration and partnership project funding. It is possible that capacity building resources could be routed through the Big Lottery and involved somehow in the 'Big Society Bank'. It is very likely that there will be an even greater emphasis on alternative methods of income generation and collaboration using new models of participatory funding.

Capacity Building



There has been a huge growth in the number of UK voluntary and community organisations that are constituency or user led in recent years. This is because of the development of relevant community interest initiatives that respond directly, and more importantly, emphatically to the needs of individuals involved with them. Many of which are often started by individuals interested or affected by the issues, because they have identified the gap through experience. This has also been affected by both the increased outsourcing of public services and the rise of localism and

participatory democracy that demands user involvement.

Along with this expansion of grass roots or front line organisations providing things directly to their community, has also seen a rise in membership and infrastructure organisations. The role of these organisations typically is to support organisational development through training, advice, raising profile, policy analysis and campaigning.



Capacity building is a blanket term for the assistance or support that is provided to organisations in order to help them improve their effectiveness and boost performance. Although some capacity building programmes are targeted solely at the personal development of individuals, for community groups the outcomes are focused on improving organisational performance and effectiveness. This can be thought of as being either about business or voice skills. Business skills refer to strategy, planning, management, income

generation, product design, marketing, quality and networking. Voice skills are focused on inclusion and diversity, partnerships and collaboration, advocacy, campaigning and ultimately the leadership of change relating to vision and your community and the people you represent.

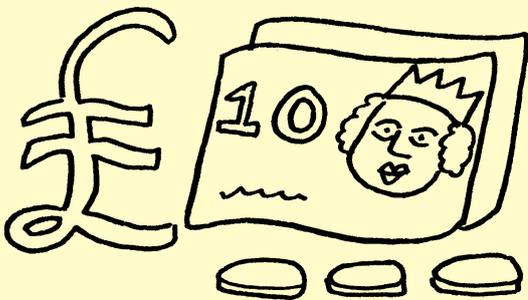
Primarily, community groups will engage in capacity building activities because they have recognised a skill gap that they believe, if filled will allow them to be able to do more, more effectively and have a bigger and better impact. The way capacity building organisations offer this support varies. Some will be very structured, offering generic training courses. Others will be more fluid focusing on challenges and opportunities facing a particular organisation, developing slow paced bespoke solutions. The take up and outcomes are variable though. This is not only because for groups with skill gaps having the time to focus on filling them can be difficult. But also because what is offered maybe too generic or mismatched to groups working in particular areas or on specific themes.

It is important to remember that capacity building makes a number of assumptions about the way organisations are run and how they should develop. It suggests growth is good and that big is better and often adopts successful approaches from elsewhere. However, we must remember that this isn't always helpful, and while it is clearly important for groups to reflect on what they do and always be ready to adapt to change, they should be careful not to do so in the shadow of someone or something else.

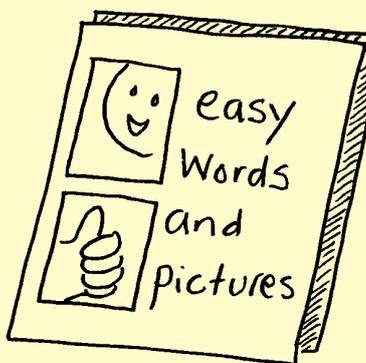
Unfortunately the way we run organisations has increasingly become

a reflection of the private and business sectors. As a result, keeping up with financial accounts, project plans, organisational reviews and quality assessment can be complicated and inaccessible. This is not because community groups are reluctant or not competent, but rather because the approach of business has a different culture and value system.

An example of this is People First, a self advocacy organisation of and for people with learning difficulties, who choose to create their annual accounts in easy read format so their members can



understand them, but Companies House and the Charity Commission won't accept them. So they have to create another version that is inaccessible for them, but accessible for someone else. With this in mind there is surely a case for capacity building to be focused on making things



easier to do, not more complicated. If we can free up the time we spend

quite honestly wasted on jargon and organisational complexity, think how time rich we could be. Organisational effectiveness can be surely improved by learning how to integrate inclusion into operating culture. This is one of many contributions that Disabled Peoples Organisations can make to future third sector capacity building initiatives.



Disabled Peoples Organisations (DPOs)

Disabled Peoples Organisations are different to Disability Charities. The distinction is that they were set up, and are run and controlled by disabled people by themselves, for themselves. The defining characteristic is that a majority of disabled people form the management board, staff, volunteer, member and user groups. The difference between 'of disabled people' and 'for disabled people' is subtle but very important because it is about whose voice it is that speaks for disabled people. DPOs therefore champion, and are committed to the human rights, equality and inclusion of disabled people as valued and respected citizens. DPOs challenge a history of disempowerment by non-disabled people

doing things 'for' disabled people, on their behalf, without their participation. While there are early examples of DPOs dating back to the 19th Century, it was not until the 1970s with the rise of liberatory identity politics that DPOs grew in number significantly. For example in 1981, in Hampshire, a number of disabled people living in a traditional residential home were responsible for significantly changing the expectations and potential of disabled people. By convincing the budget holders to hand over money and resources to disabled people directly for them to arrange their own support, 'project 81' an early DPO, set a radical social policy standard and cajoled a profession into becoming allied to its community.

This is partly why we now talk about personalisation, self directed support, independent living and all those things that look to put people first and move us away from the sloppy traditional one size fits all leftovers from the asylum and workhouse. Although DPOs can be thought today as an emerging sub

sector, they are very much embedded and connected to a social movement of disabled people asserting their civil and human rights.

DPOs are involved in a diverse range of activities and services, covering rights, employment, health, arts & culture, accessible information, campaigning, citizenship and inclusion generally. 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. However, like other community groups DPO's face many challenges in their day to day running and are increasingly losing out to bigger charities and contractors as funding arrangements change. Because DPOs are made up of disabled people they face considerable institutionalized disadvantage relating to disability discrimination and segregation. Also, as an emerging subsector with fewer infrastructure resources DPOs often miss out on developmental opportunities arising from policy changes



Added Value

The added value of DPOs comes through the leadership that emerges from disabled people coming together, sharing experiences and developing practices of inclusion. Disabled people teach others to be proud about who they are, and how we can be better about including each other in education, work, lifestyle and citizenship. Fundamentally, they show others that its ok to be a disabled person. This facilitates a unique organisational culture that embraces and values the voices and experiences of disabled people from the perspective of equality and dignity, rather than that of personal and medical tragedy. Through this DPOs become highly effective in valuing diversity, innovating inclusion and tackling disablism (disability discrimination). This can be a lifeline of empowerment for disabled people allowing them to be proud of who and how they are. Equally, organizations and individuals who engage with DPOs learn much about including disabled people, through the direct experience of those who do it every day.

DPOs possess a range of skills, supporting individuals to take control of their lives, offering peer support, advocacy and the means of empowering individuals. They understand how to make information and means of communication accessible and can facilitate participation, consultation and working across difference. They think creatively and find imaginative solutions in overcoming barriers for disabled people, but also have an in-depth knowledge of relevant legislation, policy and the local area. However, the added value of DPOs is not easily measured.

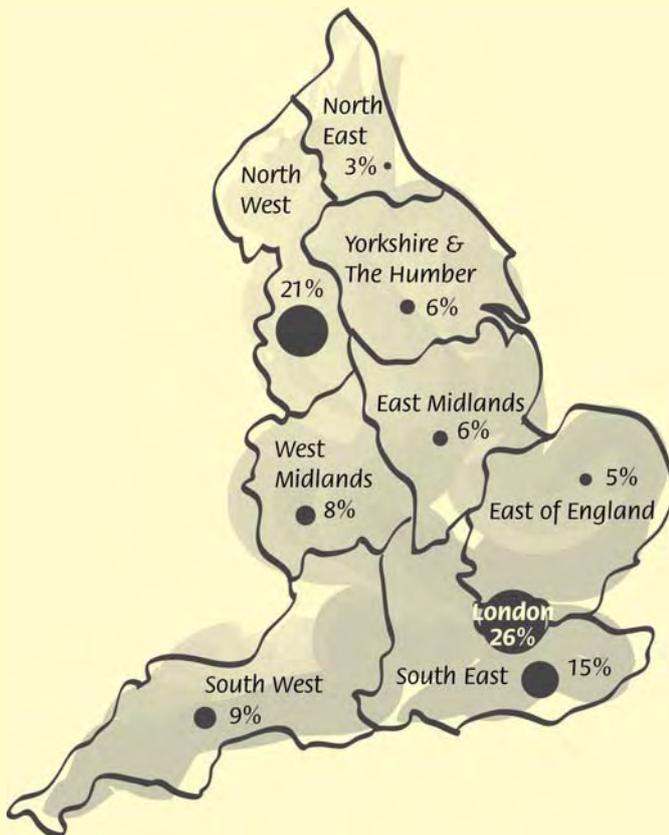
DPOs state they find it difficult to be spend time even thinking about how they would measure their added value. This is likely to be especially difficult to integrate measures of alternative value within working practices and existing value systems.

Disability Equality North West

Disability Equality North West (DENW) was set up in 1995 by 6 disabled people from Preston, who identified problems in accessing information. Their aim is to 'further the human rights of disabled people across the North West of England. They have 6 full time & 4 part time staff, 40 Volunteers, 8 trustees and 2000 individual members, all of whom are disabled people. They also have 50 group members (DPO's) and 150 associate members. Their information and advice service answers over 250 enquiries a month. In addition they run a young disabled people's project, self directed support user groups, health and wellbeing groups. They support other local DPOs and are involved in influencing policy locally, regionally and nationally. This year they have an income of around £300'000 from 13 different funders and are currently funded for only around 75% of what they do. DENW's CEO Mel Close says what DPOs want from capacity building initiatives are 'less courses, more conversations'. A one size fits all approach to training and support can not help tackle the need for a group to understand its strategic position, and develop a unique community leadership role for the benefit of its membership.

Geography

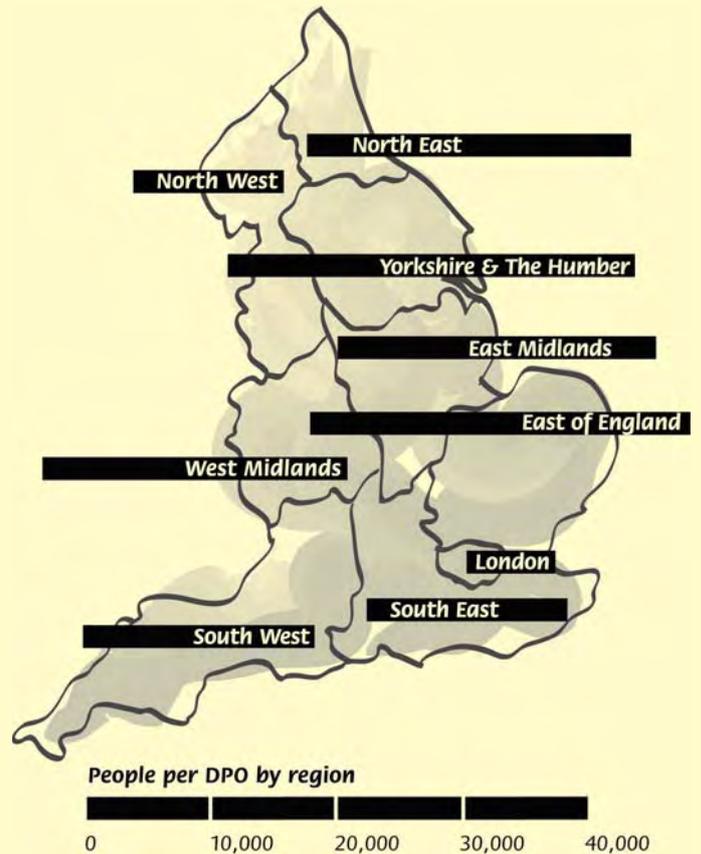
The actual number of DPOs in England is unknown, with estimates of between 700 to 1000, with significant annual fluctuation and variation (Maynard Campbell, S., Maynard, A. & Winchcombe, M. 2007 and Disability LIB 2007). Indeed this may be an under estimation considering the diversity of DPOs that include small un-constituted self help groups meeting in someone's home to large regional centers for independent living or national umbrella organisations. The sector is fluid with projects and organisations rapidly emerging and disappearing due to changes in funding.



The following table shows the spread across England, using the Regional Government Office areas and based on Disability LIB's contact with over 500 DPOs. While useful to highlight issues for DPOs it should be noted further research work is needed to map these

organisations, such as the current survey being carried out by NCIL (2010).

The North East has the least number of DPOS with 3%, the lowest population [2.5mil], but the highest number of people of working age claiming social security benefits [18%]. While London has 26% of DPOs, the highest population [7.6mil], and 13% of people of working age claiming social security benefit.



There are 11 million disabled people in Great Britain according to the Family Resources Survey (FRS) disability prevalence estimates of 2007/8. Like DPOs, the actual number is unknown as this is based on a sample selection and because disability and impairment are difficult to categorise as they encompass a broad range of issues and experiences (ie mental health, cancer, addiction, neurodiversity, etc). However, using this figure and those of DPOs from Disability

LIB the following shows the number of disabled people per DPO in each English region.

In London there are 7k disabled people per DPO, while in Yorkshire and the Humber there are 33k. Although in London there are a higher number of national organisations and infrastructure opportunities to develop and sustain are likely to be easier. Overall, there are 20k disabled people per DPO using this data.

Income



Figure 2. 2009 Income in Millions of 8 Disability Charities & 100 DPOs.

Overall the income of DPOs is low. Groups can be categorised as, Unfunded –self help groups, informal networks; Small – up to £15,000 per year access groups, self-advocacy projects; Medium – to £100k, small information, advice and advocacy community based projects; Large to £1.5 - £2 million, operating regional with a wide range of independent living services. National DPOs will often have an income of between £100k and £200k.

Using a sample of 100 DPOs in the Medium and Large category and financial data from the Charity Commission DPOs income grew from £30million in 2005 to £40million in 2009. However, this growth is unevenly spread with 40% of groups showing reduced income, with 15% of these being reduced by more than 50%. There also are significant regional discrepancies. DPOs in the East of England grew by more than half, but those in the East Midlands and North West showed a decrease. Overall, regional centers for independent living providing a range of different services do best, while small single issue campaigning groups and national organisations struggle most.

The size of the health, social care, independent living, disability equality and related industries is huge. In 2007-2008 gross total expenditure by councils on social care was £20.7 billion and 12.0 billion was invested in private and voluntary sector providing social care services. The incomes of 100 DPOs taken together amount for only 20 to 30 percent of the largest disability charities. The DPO with the highest income in 2009 was just over £2 million.

Mainstream Capacity Building and DPOs.

Recent market research by NCVO with over 1200 organisations highlighted funding, governance and leadership, workforce and legal as the most important capacity building issues. It is also likely that for the future collaborative working, information technology and campaigning will be important too. While there has been some support from government policy for DPOs (see 'Improving the Life Chances of Disabled People') that has contributed to some growth in their income and activities, there is very little research and understanding of the capacity building needs and value of this emerging subsector. From the research that does exist (see 'Supporting Equality Groups'), the need for mainstream capacity building work to ensure accessibility of their resources to DPOs is highlighted as a result. DPOs face particular challenges in terms of governance, management and employment issues due to skill shortages and the extra costs of access needs of disabled trustees, staff, volunteers and members. This can hamper efficiency and places DPOs at a significant disadvantage, as the recent 'Building Our Futures' project highlighted. Furthermore, targeted work is needed to develop and evidence the unique role and value DPOs offer, so as to raise their profile. This is so that funders and commissioners understand DPOs and ensure they can compete equally and fairly in future development opportunities.

What are the capacity building needs of DPOs?

Participants at our roundtable event identified the following themes as being key capacity building issues for DPOs.

Disability Discrimination

Disabled people face disadvantage across the life course, in education, employment, citizenship and lifestyle. Skills development and capacity building programmes need to recognise and accommodate this to include disabled people equally. A lack of understanding about disability and preconceived ideas of normality about how people should engage in, training sessions for example, can prevent DPOs taking part in them.



Accessibility

There are extra costs associated with disabled peoples access that are very often not accounted for. If these are not available, participants from DPOs that need transport, sign language interpreters or easy read information will not be able to attend and engage with mainstream capacity building events. Also, funding programmes that have an fixed upper limit will often require 'access costs' to be included within this. This ultimately means DPOs are accessing less income as a result of access costs.

Civil Society Profile

While disability enjoys a high profile within civil society, and indeed makes up a billion

pound industry, DPOs are not well known and recognised as distinct within it. As a result mainstream organisations may not recognise and value the difference. This can mean DPOs may miss out on opportunities and, their viewpoint is not understood. Indeed considering the size of the industry, disabled people are considerably under represented and have little control over traditional disability charities and organisations. Additionally, those involved with DPOs, may not see themselves linked to broader national networks and movements.



Added value

The unique and specific value of DPOs comes from the leadership, pride and learning disabled people demonstrate to others by showing how equality and inclusion can be done. Basically, DPOs demonstrate that disabled people are a 'normal' part of everyday life. However, this added value is not easily measured or indeed understood. While some established DPOs have used specific examples of their work and successes to secure income, future capacity building work is needed to develop this.

Networking

There is need to develop positive relationships and networks to bring

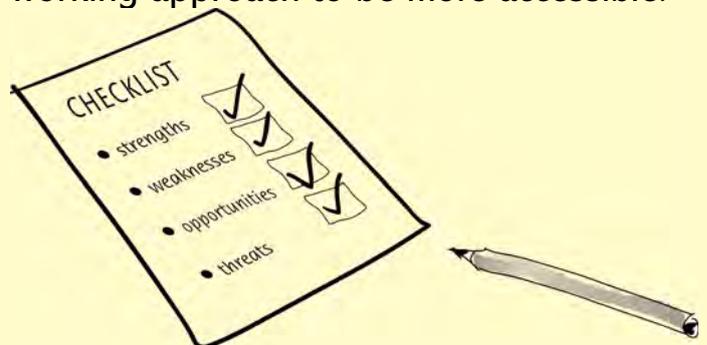
mainstream organisations, diverse disabled people and DPOs who work locally, regionally, nationally, internationally and on specific interests together. This will increase both the profile, voice and representation of disabled people and the understanding of DPOs in wider forums.

How can mainstream Capacity Building organisations engage and work with DPOs?

Participants at our roundtable event identified the following as key issues for capacity building organisations so as to be able to engage and work with DPOs.

Dialogue

DPOs and mainstream capacity building organisations will improve understanding of each other by engaging in an ongoing dialogue. This needs to allow space for each to get to know one and other, establish trust, respect and understandings of background, motivation, similarities and differences. One mainstream capacity building organisation stated that through ongoing communication with a DPO they had been able to reflect and adjust their working approach to be more accessible.



Another said they had not had the chance previously to understand the difference between DPOs and Disability Charities. DPOs often find themselves isolated from

infrastructure support networks. A DPO running a capacity building programme stated that they had contacted 33 CVS' in their region with a proposal to work together, but had no positive responses.

Working Relationship

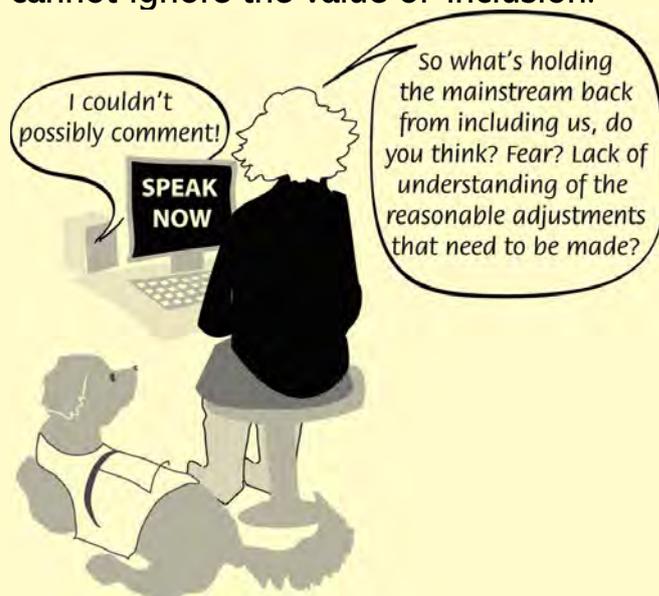
Through a combination of low profile, lack of understanding of what each other does and resources available, DPOs and mainstream capacity builders often don't engage. Mainstream capacity building organisations could work with national DPOs to deliver train the trainer versions of their courses to improve take up. Developing further collaborative projects, working on DPO specific issues, like understanding added value and survival scenario planning, would also be of benefit. Also, ensuring Disabled People and DPO representatives are involved in more relevant management and advisory boards. Mainstream capacity building organisations should recognize the established relationship DPOs have with each other and could work with regional and national DPOs to deliver train the trainer versions of their courses to improve take up.

Equality Impact

There is a sense that mainstream capacity building organisations do not necessarily understand the equality and human rights messages that DPOs make. This is not to say they are not committed to them, but rather have not heard them before or had the chance to engage with them. CVS say they want to work with DPOs, but are not sure how to. If DPOs had the opportunity to undertake an equality impact assessment of the courses and resources a mainstream capacity building organisation offered this may develop this understanding.

Inclusion

Often DPOs get boxed off as too specialist and the knowledge they can offer mainstream organisations on how to address issues like disability employment, citizenship and inclusion is missed. Considering the spending power of disabled people is estimated at £80 billion pounds per year, organisations cannot ignore the value of inclusion.

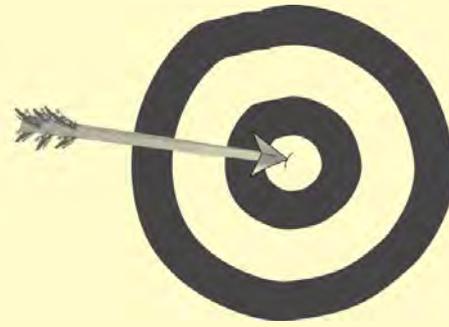


In short, DPOs can help mainstream organisations to be more inclusive as services, employees and ethical organisations. However, part of this also requires leadership to identify and demand structural and cultural changes. Like, for example developing inclusive schools or flexible working contracts.

Funding

Mainstream capacity building organisations are likely to have greater influence with funders than DPOs. Often funders will not understand the capacity building and funding needs of DPOs. Greater opportunity should be given to DPOs to access, influence and evaluate capacity building funding opportunities for work with disabled people and the wider community.

Priorities, Implications & Actions



Drawing on existing research mentioned earlier, current issues and the themes discussed during the roundtable discussion the following priorities, implications & actions were identified.

Priorities	Implications	Actions
Examine impact of spending review, and engage in OCS infrastructure consultation for DPOs.	Impact of cuts and scenario planning options understood by DPOs, and influences OCS consultation.	NCVO and Disability LIB to examine cuts, develop DPO survival scenario and engage with Capacity Builders, WRC, & NEP for OCS consultation.
Increase profile, understanding and research data of DPOs as emerging subsector.	DPO profiled as an emerging subsector, its capacity building needs known and added value evidenced.	Disability LIB, NCIL and NCVO to collate and publish existing DPO research sources and relevant data.
Develop method to capture 'added value' of DPOs.	DPO added value understood on local and national scale.	Disability LIB, NCIL and DPOs develop project with NCVO, ACEVO and others.
Undertake equality impact assessment for DPOs of mainstream capacity building programmes.	Accessibility of range of capacity building programmes assessed and adaptations understood.	Disability LIB, UKDPC, People First, WRC and NEP review and make recommendations.
Increase profile, and use of capacity building programmes and funding opportunities within DPOs.	Existing programmes and initiatives promoted to DPOs, which increases uptake.	Disability LIB to promote capacity building initiatives by NCVO, ACEVO and others to 500+ DPOs.

Disability LIB will coordinate and follow up on the above priorities and actions.

Conclusion

This position paper explored challenges and opportunities for DPOs and mainstream capacity building organisations alike when working together, and the benefits for them to do so. Having outlined current issues for the third sector and capacity building organisation the characteristics of Disabled Peoples Organisations as an emerging subsector were explored. From the discussion a number of priorities and actions were identified. It is important that these are taken forward so as to both help forge useful relationship between DPOs and main stream capacity builders, as well as developing strategies for the wider third sector to become more inclusive of diverse and disabled people.

References

Disability Action in Islington & Trust for London, (October 2010) Building Our Futures; Research into the employment and human resource needs of Deaf and Disabled People's Organisations

<http://www.trustforlondon.org.uk/new/Building%20Our%20Futures.pdf>
Accessed October 2010.

Disability LIB, (2007). Thriving and Surviving; Challenges and Opportunities for Disabled People's Organisations in the 21st Century. http://www.disabilitylib.org.uk/images/stories/DisabilityLIB_report.pdf Accessed August 2010.

DWP Report 2008-09, Family Resources Survey.

http://statistics.dwp.gov.uk/asd/frs/2008_09/frs_2008_09_report.pdf Accessed October 2010



Maynard Campbell, S., Maynard, A. & Winchcombe, M. (2007) Mapping the capacity and potential for User-led Organisations (ULO) in England. Department of Health. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_078538 Accessed August 2010.

National Equality Partnership, (August 2008). Supporting Equality Groups: An overview of support to the diverse third sector in England: http://www.wrc.org.uk/includes/documents/cm_docs/2008/s/supporting_equality_groups_nep_august_2008.pdf. Accessed October 2010.

NCVO, (2010). The UK Civil Society Almanac 2010.

NHS Information Centre for Health and Social Care, (2009). Personal Social Services expenditure and unit costs, 2007/08.

Prime Minister's Strategy Unit (2005). 'Improving the Life Chances of Disabled People' London. The Stationery Office.

Notes

The roundtable event was organised by Disability LIB, held at NCVO and was attended by representatives from the following organisations. ACEVO, Black Training & Enterprise Group, Capacity Builders, Council of Disabled People Warwickshire & Coventry, DIAL UK, Disability Action in Islington, Disability Equality North West, Equality National Council, Liverpool Charity and Voluntary Services, National Equalities Partnership, NCIL, NCVO, Norfolk Coalition of Disabled People, Office for Civil Society, People First, Pilotlight, The Vassal Centre Bristol, UKDPC and the Women's Resource Centre.



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