



Disability

Listen Include Build

Disability LIB: Legacy and Learning

Executive Summary



Disability LIB, September 2011

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Executive Summary

This report highlights the activities, achievements, learning, legacy and recommendations made from the BIG lottery funded Disability LIB project (2007 - 2011). A key element of the lasting legacy is an interactive web resource with 30 short films about Disabled Peoples Organisations (DPOs) and capacity building. In this report are number of quotes from disabled people from DPOs who we engaged with and were involved in the project. These are taken from the transcriptions from the films, comments we heard, notes we made and feedback we received. Further information and detail is included in the full report available from www.disabilitylib.org.uk.



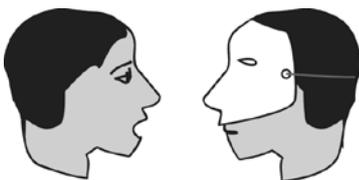
"We think it's very, very important that disabled people are in the driving seat. Because if we're going to change society so that disabled people are equal, then disabled people need to change the world. Other people can't do it for us. We need to do it for ourselves. We need allies. But it has to start from disabled people."

Disability LIB

“We need to campaign more and more to try and make sure that disabled people are included in society fully and they have choice and control over what they do.”



“You know we’re living in a world where campaigning has become kind of a dirty word really. The government doesn’t want any real challenge, it wants everything to happen easily and it wants everything to happen by the faceless private sector.”



This executive summary highlights aspects of our work, learning, and the legacy that remains.

Disability LIB is a partnership project of seven organisations supported by the Big Lottery Fund to provide a range of capacity building support to Disabled Peoples Organisations (DPOs) in England. The partnership is made up of the Alliance for Inclusive Education (ALLFIE), Disability Awareness in Action (DAA), Disability Equality North West (DENW, formerly Preston Disc), Equalities National Council (ENC), People First, Scope, and the United Kingdom Disabled People’s Council (UKDPC). DPOs are run and controlled by disabled people, focused on challenging discrimination and promoting inclusive living and represent a distinct and specific community within civil society. Between 2007 - 2011 the Disability LIB partnership was awarded £4.5 million from the Big Lottery Fund in two phases.

During the first phase we produced a sector wide audit of DPOs. The report, ‘Thriving and Surviving’ (2007) demonstrated how DPOs are disadvantaged and restricted in their development in a range of areas. This included the additional costs of access, commissioning and competitive tendering processes, governance and leadership, as well as the exclusion of DPOs from mainstream capacity-building activities.

In the second phase of the project the seven partner organisations delivered a range of training and capacity building support in relation to their area of expertise with the overall objective of enhancing the sustainability of DPOs in England.

What we did

Over the three years of the Disability LIB project we provided a range of capacity building training and support. Our activities and achievements include:

- Capacity building work with 210 DPOs providing a range of bespoke support and engaging with over 900 disabled people.
- * Facilitated 65 DPO specific events, workshops and seminars, including eight intensive human rights residential training sessions attended by 38 DPOs.
- * Produced 30 short films about DPOs and capacity building issues showcasing the activities, added value and experience of disabled people engaging in organisational development.
- * Developed over 60 toolkits and resources covering a range of topics including human rights, project planning, governance, income generation, inclusion and diversity and leadership.
- * Undertook DPO specific research and analysis focusing on young leaders, diverse communities in the North West, future strategic drivers of DPOs and access to mainstream capacity building.
- * Ran leadership initiatives with young disabled people, BME disabled people and senior representatives in DPOs.
- * Distributed over £60k to 40 small DPOs to undertake tailor made capacity building solutions, including consultation events, developing websites and management and trustee training.

Typically unfunded, establishing or DPOs experiencing difficulties engaged in our bespoke support sessions, whereas training sessions and workshops were attended by a broad range of DPOs. Our work with Lancashire Centre for Independent Living (LCIL) is an example of our bespoke capacity building work.

“Capacity building isn’t about today, it’s about the future and at this moment in time when everything’s so uncertain, actually building capacity so that you are a strong viable organisation is more important than ever before. It’s about our futures, as a collective.”



I think leadership is the key to unlocking the amazing amount of talent, disabled people’s talent that exists in this country and if we can support individuals to lead Disabled People’s Organisations then you will get stronger, better, more influential Disabled People’s Organisations, which will then drive much more influence and better services for disabled people, enhancing their everyday lives which is what we’re about.”

“It’s great to have someone who understands the issues that smaller disability groups face and other discrimination issues. It is very helpful to have an organisation you can go to for support”



“We are a strong, vibrant movement of people and we’ve got to make sure that we are at the forefront of government change, legislation change, especially now with personalisation. It’s there because of disabled people’s organisations and disabled people who weren’t happy with the “service” of what they were getting. We’ve got to make sure that we’re firm in what we expect to happen to us.”

Disability LIB supported LCIL to review their organisations, make plans for the future and ran a focus day and other training sessions for LCIL staff, trustees and volunteers.

“It was good to have somebody that had the knowledge of where we needed to be. What our policies needed to be, how our governance needed to be, because it was all new and with the memorandum and articles and association it was just jargon. We didn’t understand what it was for or why we needed it so when Disability LIB came in, the first thing they did was a diagnostic report of the whole organisation. This looked at what we didn’t have, what needed to be in place and from there we went through the process of putting those things in place. And also helping us understand what it all meant. When we first came on as a board although collectively we had a lot of good work experience and knowledge as a board we didn’t really have any knowledge of what the board should do or how it should run the organisation. It was quite a chaotic, manic focus day but I think if we hadn’t had it, it would have been a complete melt down because there was a lot of things that the staff were saying, even though we were coming into the office quite regularly at the time, myself and the company secretary, they weren’t saying what the problems were or what the issues were. They were just bubbling under the surface and then on that day everybody was saying what they actually felt and they weren’t afraid to say it. And then what they realised was, actually that’s the same view and vision that the board had. So it was a big learning curve that really the staff hadn’t had that communication. But once you find that once you’ve got everything in place and everything’s running smoothly the workload that you’ve got does come down a lot. It’s not as frightening as what you think.”

Our experience of delivering capacity building support is that a positive, flexible yet persistent approach, that is embedded in a disability rights perspective, is most effective.

By adopting this approach we believe that our work has enhanced the sustainability of DPOs in England by achieving two key overarching outcomes.

The first is to have raised the profile of DPOs as distinct, innovative and genuine agents of disabled people's inclusion and social change within the wider voluntary and community sector and some government bodies.

DPOs offer an authentic environment for service delivery and are gaining recognition for their unique place in developing services in line with user need. We believe that through our work we have inspired and given confidence to many DPOs to recognise the role and positive value they can offer.

Secondly, and more importantly, we have facilitated an independent space of and for DPOs that champions disabled peoples voice's to define and articulate their vision of change. This has resulted in the vital reposition and refocus of some DPOs, and allies, as human rights organizations.

This is where we believe we have had most impact, on groups, and the wider disabled people's movement for the future, as equality initiatives and protections are challenged by ever reducing resources and significant policy changes.

"The more understanding we've got about the human rights of disabled people the better quality of information, advocacy and service we can deliver."



"The UN Convention on the Rights of Persons with Disabilities confirms disabled people's right to life, equality, integrity, freedom and security. It's an essential tool for Disabled Peoples Organisations. It's another tool in the armoury and they need this weapon."

What we learnt

“There are two things that I think Disabled People’s Organisations are about ultimately. Challenging disablism and about promoting inclusive and independent living. And that’s it really!”



“The social model of disability recognises that disabled people are disabled not by their impairments or health conditions but by disablist attitudes and by organisational and physical barriers in society.”

In addition to furthering understanding about the characteristics of DPOs, some details of which are included in the full report, there are several aspects of learning that we take from this project and believe are important to share.

Principles - Through our work we have emphasized the importance of recognising disability as a human rights, and international issue. In order to be more influential it is vital that DPOs are principled and persuasive in their articulations about how the lived experience of discrimination manifests for a broad and diverse range of disabled people.

Profile and knowledge - Unfortunately the profile of DPOs remains low. While we have seen in recent years an emerging body of research and specific initiatives concerning DPOs, there is a real need for further work in this area to highlight the added value, market offer and developmental issues for DPOs.

Partnership working - Those involved in Disability LIB recognise the huge value of working in a partnership to deliver a large scale project. This has resulted in valuable learning about delivering support to DPOs, as well as organisational resilience, creating supportive links and enabling new knowledge about distinct experiences of disabled people to be shared between organisations.

Future issues - Through our work we note a number of needs relating to DPO’s capacity building issues. These include further promoting the unique role, profile and added value of DPOs, and giving greater attention to inclusion, diversity and work that addresses aspects of multiple discrimination. There are also very distinct organisational issues about governance and human resources, funding and sustainability, networking, and ensuring an up to date and DPO specific analysis and dissemination of policy, legislative and other changes.

Our Legacy

Along with the recommendations we make, our shared learning and knowledge and the impact of our capacity building activities, a key element of the lasting legacy is an interactive web resource with 30 short films about Disabled Peoples Organisations (DPOs) and capacity building.

The films are divided into four sections,

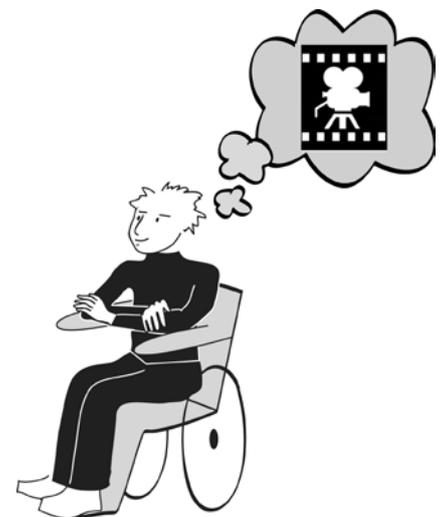
- Disabled Peoples Organisations;
- Human Rights, Equality and Campaigning;
- Running a Disabled Peoples Organisation; and
- Leadership.

The films highlight work undertaken by Disability LIB over the past three years (June 08 - May 11) and contain a number of personal stories about organisational change and the work of Disabled Peoples Organisations..

We made the films as we wanted to highlight some of the challenges facing Disabled Peoples Organisations (DPOs) and to celebrate the unique value they have in making sure disabled people are at the forefront of running their organisations, directing services and influencing and delivering social change that creates inclusive and accessible places to live, learn, work and play.

Along with the films are over 60 toolkits and resources to download covering a wide range of capacity building issues.. The films are for DPOs to use to promote their work in presentations, for training and other activities.

“Film is one of the greatest techniques of communicating to the outside world. It helps us immensely to become more aware of what we are. It helps me in many ways in understanding how it works to be disabled.”



“We can use this as a tool in future meetings with our local council”

Recommendations

We make a number of recommendations based on the experience and learning of our work with DPOs of the last three years. These recommendations are intended for regional and national DPOs to lead on, working in partnership with other bodies, such as mainstream capacity builders, funders and regulators where relevant. They include a number of specific initiatives that are important to facilitate the future sustainability of DPOs. Further information and detail about the recommendations is included in the full report available from www.disabilitylib.org.uk.

Access to capacity building - Mainstream capacity building organizations are often not inclusive of DPOs.

Recommendation: greater promotion of relevant and existing initiatives offered by national and local mainstream capacity builders to DPOs.

Recommendation: undertake specific profiling of DPOs by engaging with them to promote them as a distinct and specific community within civil society organizations.

Added Value - DPOs struggle to both articulate and have their 'added value' heard through lack of relevant and robust tools.

Recommendation: develop a method suitable for DPOs to calculate 'added value' measurement systems and promote this on a local and national scale.

Allies – the role of a true disabled person's ally is not well understood.

Recommendation: promote the role of allies, circulating widely, with clear examples of what it means to be an ally of disabled people, building on recent work by Breakthrough UK and others.

DPO information briefing – lack of specific policy, information and research analysis available that is relevant for DPOs.

Recommendation: develop a regular DPO information briefing and work to ensure DPOs are included in

mainstream capacity building sector publications and information.

DPO tendering and commissioning network - The process of tendering and commissioning for public sector and other contracts can be demanding and complex for DPOs.

Recommendation: Establish a network of skilled DPOs willing to collectively tender for public service commissions, alerting them to current tenders and providing facilitation and support to bid for and deliver contracts.

Human Rights - human rights legislation is currently underused by DPOs and other civil society organizations.

Recommendation: train DPOs in how to use human rights arguments and legislation in their information, advice and advocacy services, using the model developed by Disability Awareness in Action.

Recommendation: develop an organizational monitoring tool to gather data about human rights and disability.

Inclusion - there are significant areas of underrepresentation within DPOs and other civil society organisations.

Recommendation: develop a tool for DPOs to undertake stakeholder analysis to work out who is being missed.

Recommendation: review and develop guidelines for funding that ensure that projects are genuinely inclusive of the group an organisation plans to work and engage with, making this a condition of funding.

Leadership – many disabled people are not reached by current leadership and learning programmes.

Recommendation: set up and run a Community Disability Studies and Leadership programme aimed at current and aspiring disabled leaders in DPOs covering topics such as organisational management, disability history, culture and politics, critical thinking and research.

Recommendation: to review current mainstream leadership initiatives to make sure that they are inclusive of and relevant to all disabled people.

“Young disabled people are often looking for role models and if their only role models are people that are acting towards them like they’re charity cases and patronising and the rest of it. That’s not a very good role model to follow. It’s crucial for them to see that older disabled people can live independent lives.”

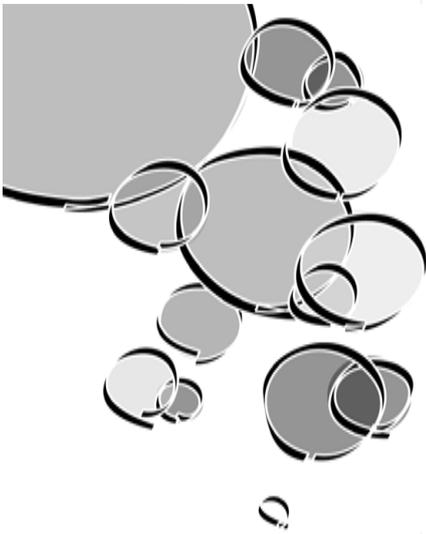


“It’s important for older disabled people not to become complacent and to get inspired by that energy of youth and those new ideas. It certainly stops us being stale and keeps us on our toes which I think is a really good thing.”

“DPOs should expand their networks and also look at forging working relationships with the wider voluntary sector. Not just the wider impairment specific sector but looking at the non-disability sector as well. Forging partnerships of that nature will help to strengthen our voice.”

Networking – there is a lack of opportunities for DPOs to meet and share ideas, offer and receive support and experiences.

Recommendation: support and facilitate a self-sustaining local, regional and national network of DPOs, to meet for targeted events, with a clear and defined purpose, on themed topics of interest, relevant to local and regional needs, and bringing in allies from other sectors and social movements where appropriate.



Conclusion

Since the beginning of the project there have been a huge amount of political change that has had a very serious effect on disabled people. We hope that Disability LIB has been able to help to minimize these changes in relation to attitudes to DPOs, but the experience facing many disabled people remains unacceptable. To address this DPOs need to achieve greater levels of political influence so that they can continue to reclaim and articulate the diverse range of lived experiences of disabled people. This needs to be a personally proud and political powerful voice that can organise our social movement, provide a strategy for our sector and push forward the change that will create a truly inclusive and inspirational society.



“When I first came into this group I was all timid and shy but now I’m like a flower bursting out of its skin and you can’t get rid of me I’m so confident.”

The DisabilityLIB partners



Alliance for Inclusive Education (ALLFIE)



Disability Awareness in Action (DAA)



Disability Equality North West (DENW, formerly Preston Disc)



Equalities National Council (ENC)



People First



Scope



United Kingdom Disabled People's Council (UKDPC).

Further information is included in the full report and available on our website along with the films and toolkits.

www.disabilitylib.org.uk.

“So do you think that society sees disability as a weakness?”

“Yes. I think society is our weakness really...

(laughter and applause)

...the fact that the way that some people treat us and the fact that oh you can't do this, you can't do that. I think that's the main weakness that we have to deal with'. I'd say don't set yourself limits believe you can do it and you can.”

