

Count Us In

2000-2005

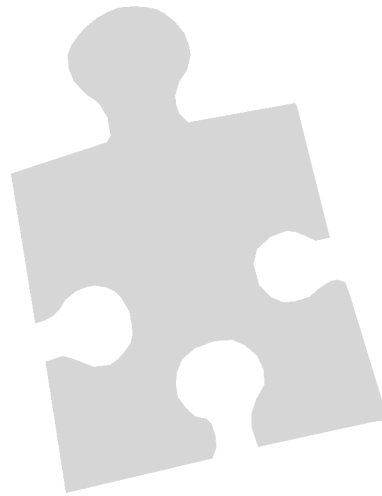
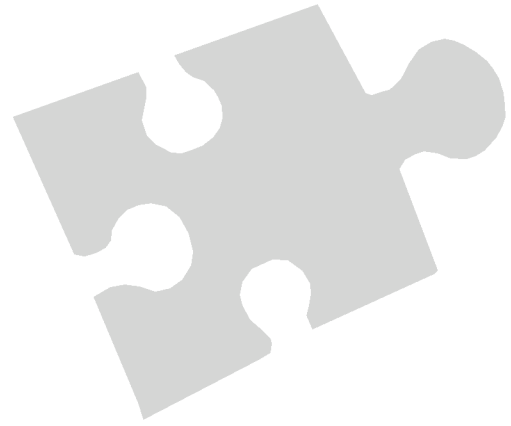
Report of the Disability
Programme



by Sioned Churchill and
Manghanita Kempadoo

This report was written by **Sioned Churchill**, Principal Officer Programmes and Evaluation, City Parochial Foundation and **Manghanita Kempadoo**, Consultant to the *Count Us In* Programme.

This report is produced in an accessible format – in Arial 18 point with easy words and pictures. Copies of the this full report - and a summary report - are available to download from the Foundation's website on www.cityparochial.org.uk or by writing to the address below.



© City Parochial Foundation, 2006

We are happy for the free use of material from this report for non-commercial purposes provided CPF is acknowledged.

City Parochial Foundation

E-mail: info@cityparochial.org.uk
6 Middle Street London EC1A 7PH
Telephone: 020 7606 6145 Fax: 020 7600 1866
Website: www.cityparochial.org.uk

Trust for London

E-mail: trustforlondon@cityparochial.org.uk
Charity Registration Numbers:
City Parochial Foundation 205629
Trust for London 294710

Contents

Introduction *page 4*

Part 1: Setting up the Count Us In programme *page 6*

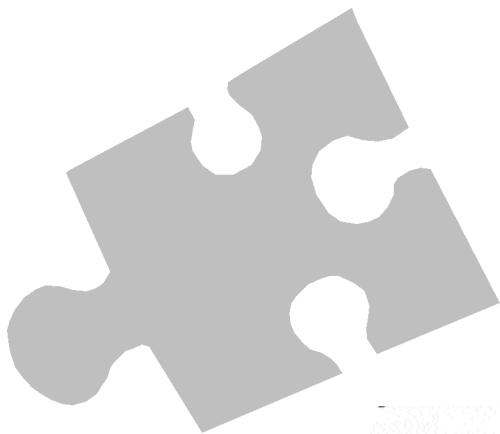
Part 2: Outcomes *page 15*

Part 3: Learning from the work *page 26*

Part 4: Conclusions and findings *page 47*

Appendix 1: Action points from People First *page 49*

Appendix 2: Glossary *page 50*



Introduction

Throughout its history, City Parochial Foundation – and its sister organisation Trust for London – have always attempted to search out needs which are often hidden and not always ‘popular’. Often this means trying out new ideas and approaches, indeed taking risks.

One such area has been to support disability organisations. In 1998 this interest led to the establishment of *Count Us In*, a special programme aimed at looking into the lack of support for small disability groups and self-advocacy groups of people with learning difficulties in London.

A very important part of this programme was to look at the needs of black and minority ethnic (bme) disabled people and other disadvantaged groups, and to develop ways in which their long term needs could be met. It soon became apparent that very



often, disability is not a priority issue for organisations tackling the wider needs of bme people: at the same time, issues of disadvantage as a result of race are not priorities for disability organisations.

Count Us In did not always run smoothly – the three

organisations in the partnership had very different ways of working, and these had to be adapted. It meant changes in approaches at times, and called for great understanding, perhaps more so than in other areas.

But overall, significant progress was made. Individuals and groups gained in confidence, and made a significant contribution towards influencing the Mental Capacity Bill, to ensure that it really did go some of the way to meeting the needs of disabled people.

This evaluation report describes the programme and the main messages. Perhaps the most important of these is that even greater effort is needed if the needs of these groups are to be met properly. While there are lessons for the disability groups themselves, there are also many for funders, voluntary organisations and service providers.



PART 1:

Setting up the Count Us In programme

Count Us In was a special programme set up by City Parochial Foundation to investigate and tackle the lack of support for small disability groups and self-advocacy groups of people with learning difficulties in London.

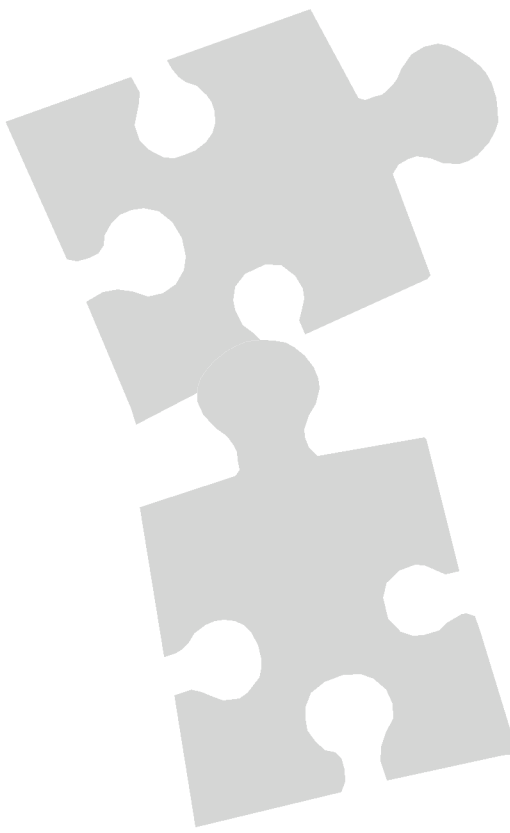
A very important part of this programme was looking into the needs of black and minority ethnic disabled people and other disadvantaged groups and to develop ways that their long-term needs could be met.

Background

City Parochial Foundation (CPF) and Trust for London (TfL), its sister organisation, fund many groups supporting people who face discrimination: black and minority ethnic (bme) communities, disabled people, refugees and asylum-seekers and women in particular.

However, staff and trustees were concerned that few applications were received from small disability groups, and even fewer from small black, minority ethnic disability groups. In previous years, outreach work had tried to tackle this, but had not resulted in an increase in the number of applications from these groups.

This special programme was a serious effort to do a big piece of work to provide practical support to these groups and to



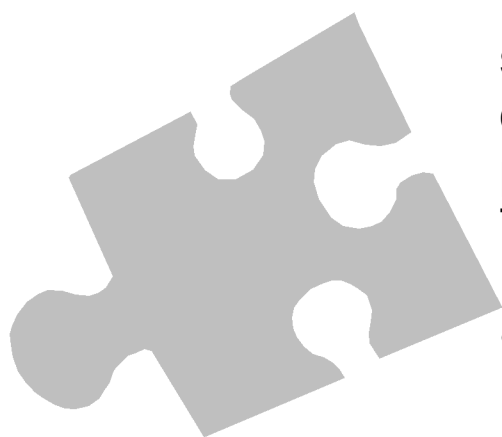


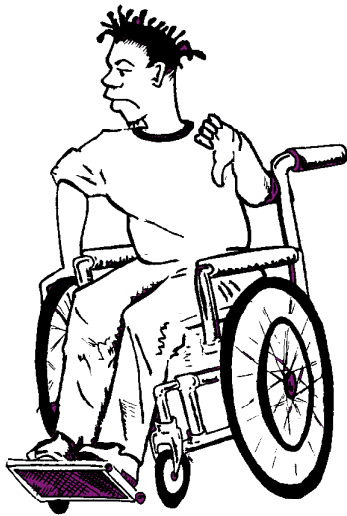
Women's group meeting at People First

learn from them about the barriers and difficulties that they experienced. A total of £1 million was invested in this work over the five-year period.

Work on *Count Us In* began in 1998. It started with discussions with organisations of disabled people and other funders who prioritise disability issues for grant-making. These discussions showed that:

- the disability sector was under-developed and unable to meet the needs of small groups;
- black and minority ethnic groups of disabled people were neglected and few in number;
- local disability groups and groups of people with learning difficulties were working in isolation of each other.





- the sector was under pressure from Government to respond to consultation papers, plans and special programmes;
- groups felt very isolated and were finding it difficult to network;
- borough-wide organisations of disabled people were not in a position to help – they were also under-resourced and under pressure from local authorities to contract for and deliver services;
- more strategic work was needed to coordinate the sector, build capacity and strengthen the support networks.

Funding and action

In April 1999 CPF awarded £600,000 over three years to three organisations – Greater London Action on Disability (GLAD), People First (a London-based organisation run by and for people with learning difficulties) and the British Council of Disabled People (BCDOP) based in Derby – to develop the work.

In January 2003 CPF agreed further funding of £400,000 for two years for Count Us In 2 – this included grants to GLAD and People First. (BCODP did not apply for further funding).

GLAD and People First were chosen

because of their track record in the disability sector and in the hope that by involving them it would help to bring together organisations of disabled people.

BCODP was included in phase one because of its national importance within the disability movement. Its role was to develop models of good practice which could be shared with the wider sector beyond London.

At this time, it was felt that there were no London-wide bme disability organisations which had the capacity to take on this work.

The Foundation also appointed Manghanita Kempadoo as consultant to the programme. She liaised closely with the organisations throughout the five-year programme.

This programme was a big step into the unknown. No one thought it would be easy and at times it proved to be very difficult. However, the programme has given many people the opportunity to push the boundaries and challenge the way things are done.

There has been a great deal of learning for all those involved and it is hoped that by sharing these lessons learnt with others, the work to support small black and minority ethnic disability groups, and self-advocacy





groups can continue.

What Count Us In aimed to do

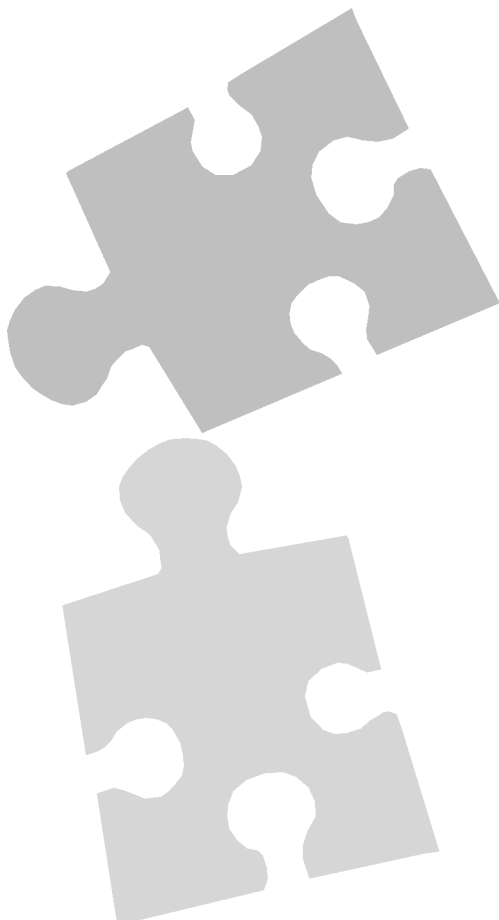
The main aim of *Count Us In* was to put in place sustainable support for small, local disability organisations in London, in particular organisations of black and minority

ethnic (bme) disabled people, and self-advocacy groups of people with learning difficulties, in order to provide an effective and independent voice for these marginalised groups of disabled Londoners.

The objectives

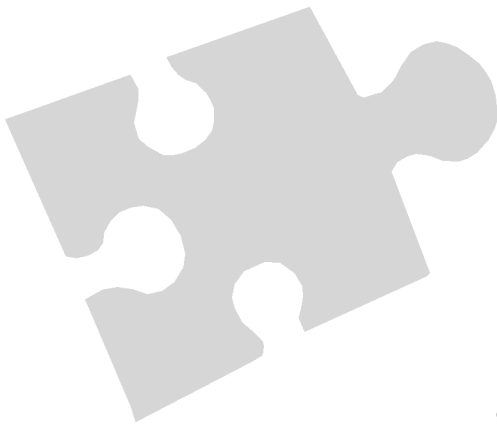
Phase one 2000-2003

- to provide support to small disability groups, and in particular to black and minority ethnic disability groups;
- to develop a database of small, black and minority ethnic, and self-advocacy disability groups;
- to provide disability equality training and advice on best practice to councils of voluntary service and other second-tier organisations;
- to increase the number of funding



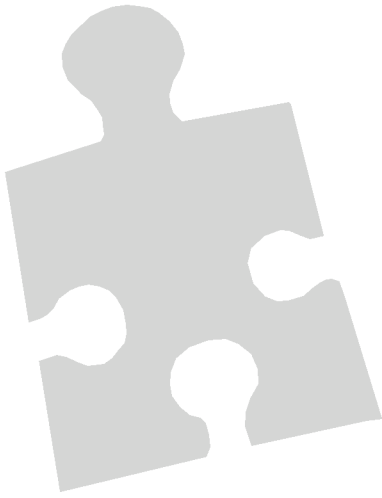
applications made to the Trust for London and other London funders, by small black and minority ethnic disability groups;

- to share and promote good practice within the disability movement and the wider voluntary sector by organising regional seminars;
- to provide support to groups of people with learning difficulties in London on policy and campaigning;
- to provide an opportunity for people with learning difficulties to have a real say in the future development of self-advocacy;
- to provide accessible information to groups of disabled people and people with learning difficulties in London about central and regional government issues and changes;
- to publish practical guidelines on the development and equality issues based on the work of the programme.



Phase two 2003-2005

- to develop and maintain a programme providing in-depth support to build up the skills of small black and minority ethnic disability groups;
- to provide support and training for



capacity-building organisations, such as councils for voluntary service, so that learning from the *Count Us In* programme could change their practice;

- to develop a functional black and minority ethnic disability forum in London;
- to set up and run a London Campaign Network;
- to act as a model for regions nationally;
- to support London self-advocacy groups to develop in a user-led way and to become independent;
- to develop work with new black and minority ethnic groups and other marginalised groups;
- to make sure that support agencies and other organisations in London understood

People First London Campaign at work



the access needs of people with learning difficulties.

Establishing the partnership

It was agreed at the start of the programme that a Policy and Development Committee would be set up and this should include representatives from People First, GLAD, BCODP, and City Parochial Foundation.

The purpose of the Committee was to discuss and agree overall policy on the different areas of the work carried out by each organisation; to agree programmes for joint working; and to review work carried out by each organisation.

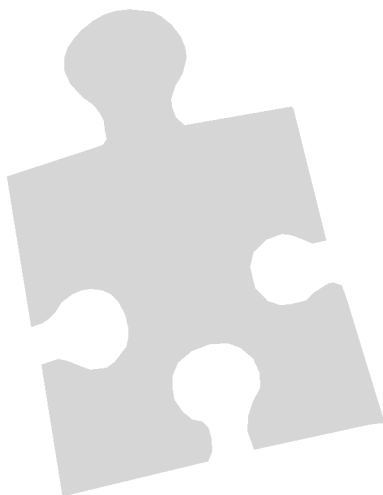
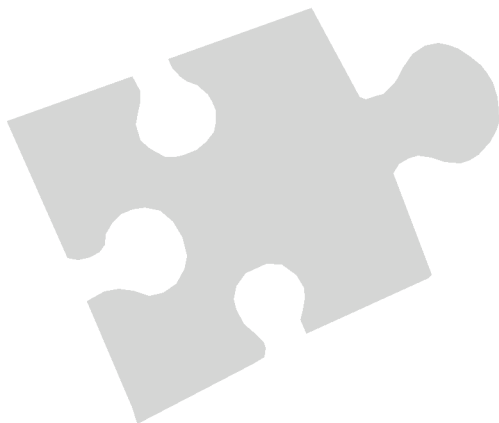
The Committee met quarterly at GLAD's offices. At the start of the programme it was decided to invite representatives from the Black Disabled People's Association and the London Voluntary Service Council to join the Committee. In phase two, representatives from the *Count Us In* Forum were invited to join the Committee. The *Count Us In* Forum was set up to provide an opportunity for bme disability groups to meet together so that they could strengthen their networks and discuss relevant issues. The Forum was supported by the GLAD workers.

Role of City Parochial Foundation Representatives of City Parochial

Foundation, including one of its Trustees, Jane Wilmot, who is disabled, attended the Policy and Development Committee.

These meetings gave everyone a chance to discuss how the work was progressing and any difficulties that people were having. CPF was keen to learn from the work and to work in genuine partnership with the three organisations.

In between these meetings the consultant to the programme, funded by CPF, met each of the organisations to discuss progress. This meant that any problems could be discussed at an early stage before they became serious. These meetings meant that the organisations and the consultant could decide how best to sort out particular difficulties.



PART 2: Outcomes

Work with small black and minority ethnic disability groups

This was the main area of work for GLAD.

Support has been provided to 85 groups over the five years which helped them raise £467,000. In total it has had contact with 118 black and minority ethnic disability organisations.



The support provided included fundraising advice, assisting with organisational issues and strengthening management committees. Training was also provided on race and equality issues.

The development workers also tried, wherever possible, to link groups with capacity-building and fundraising support agencies in their area, though with mixed success.

Although some 157 small black and minority ethnic disability groups in London have been identified, it is thought that the number active bme disability groups in London is much fewer in number.

Support has been given to disabled people from the following communities: African and Caribbean; Chinese; Vietnamese, Kurdish, Iranian, Somali and other refugees and asylum seekers; gay, lesbian, bisexual and transgender groups; black and minority

ethnic groups from the deaf community; and mental health groups and individuals with learning difficulties. Support has also been given to parents' groups.

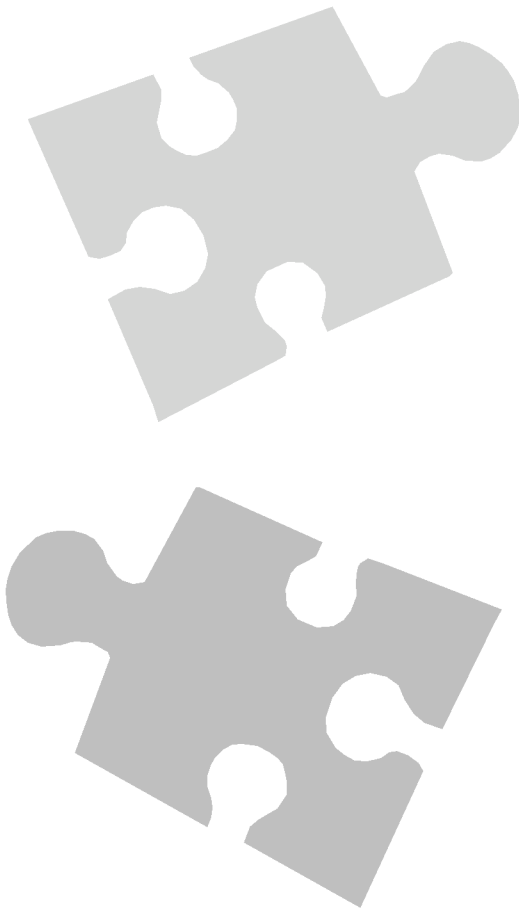
The majority of work in this area has been with black-led disabled people's organisations, but support has also been offered to individuals from black and minority ethnic communities working in non-black led organisations. Some individuals are overwhelmed by the tasks set for them by these organisations and feel isolated.

Work to establish a pan-London black and minority ethnic disability forum

The *Count Us In* Forum was established early on in the programme. The aim was to provide a space for small bme disability groups to come together, share their experiences, skills and knowledge with a view to strengthening their collective voice. This has not yet been achieved.

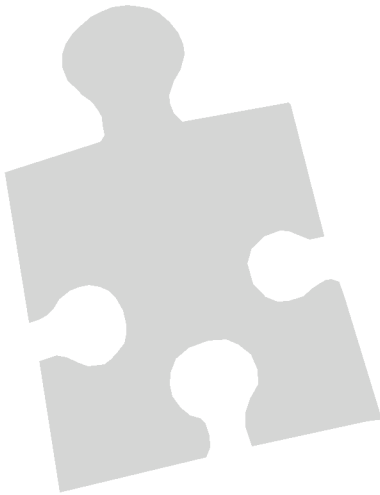
Since early 2005, more focus has been put on establishing this forum, and the new development worker at GLAD took the lead in organising meetings and promoting the forum to all the organisations on the *Count Us In* database. New members have been recruited who are keen and enthusiastic.

Several meetings have been held to agree the terms of reference and a name for the



forum, something which has revealed tensions.

There are two competing views – those who do not see themselves as part of the black movement, that is, people from non-black and minority ethnic communities who want this to be reflected in the name of the Forum. Others feel that the Forum should make a political statement about being part of the wider black movement sharing a common experience of oppression and discrimination. It would be unfortunate if this debate was to hold back the development of the Forum and a decision needs to be made quickly one way or another.



Work with self-advocacy groups of people with learning difficulties

This was one of two main areas of work for People First.



Sixteen self-advocacy groups in London have been given intensive advice and support, in particular on business planning and fundraising.

Training packages on management committee skills, recruitment and fundraising have been produced. Three self-advocacy groups are using the *Count Us In* information to become independent organisations. Newham

People First was the first one to become independent.

New groups are developing: for example the Kensington and Chelsea users have taken control of their own group which was previously led by support workers.

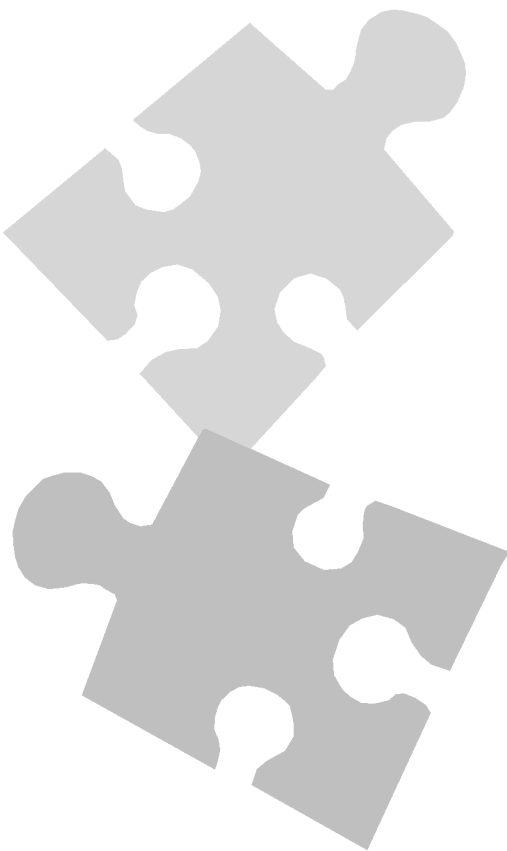
There is evidence that groups are growing stronger and making challenges for themselves. This is based on the letters of complaint sent by groups to the Disability Rights Commission and copied to People First.

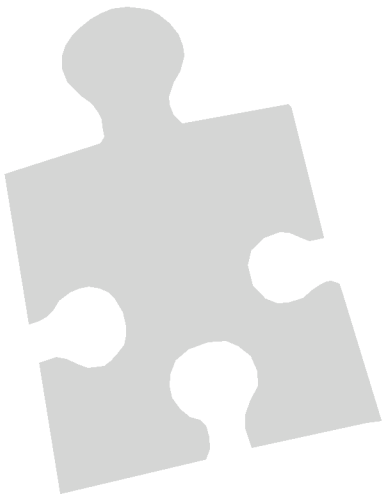
Feedback from groups indicates that they are being listened to and that funders are more supportive. Groups also stated that they were more confident and aware of issues as a direct result of this support.

Establishing a campaign network

This was the second main area of work for People First.

The London Campaign Network was launched at a conference held at City Hall in July 2003, attended by 60 people. This provided an opportunity to highlight the priority issues for the Campaign Network, which were transport, crime, people's rights, employment opportunities and accessible information.





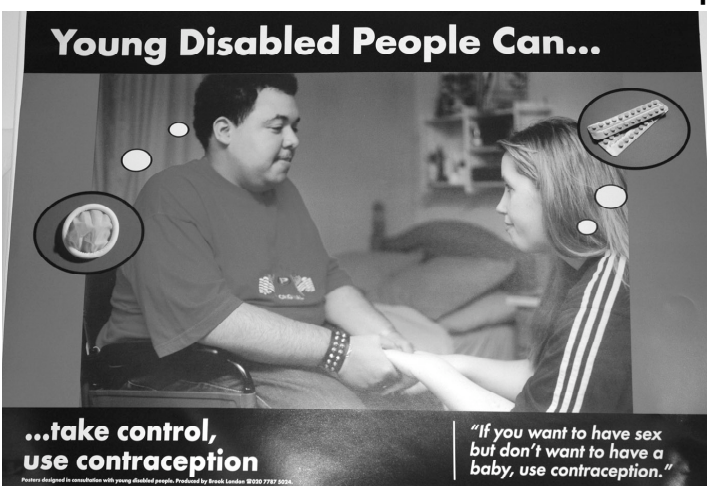
Two further conferences were held, one on crime and safety with speakers from the Metropolitan Police and Victim Support, and the other on transport, with representatives from Transport for London. Both the Metropolitan Police and Transport for London made a commitment to improve the training of their staff and to ensure that they were more aware of the needs of people with learning difficulties.

As a result of this work Disability Croydon is now delivering disability equality training for Croydon Police and People First has a representative on the Metropolitan Police's Independent Advisory Group.

A campaign pack has been produced and is now being used as a training tool for members of the Campaign Network and by local People First branches.

Several local groups have also established their own campaigns. In Barnet, the group is campaigning against the poor

employment practices of some companies employing people with learning difficulties in the borough. In Islington, the focus is on voting rights due to the fact that many people living in residential homes were unable to vote because they did not receive voting cards.

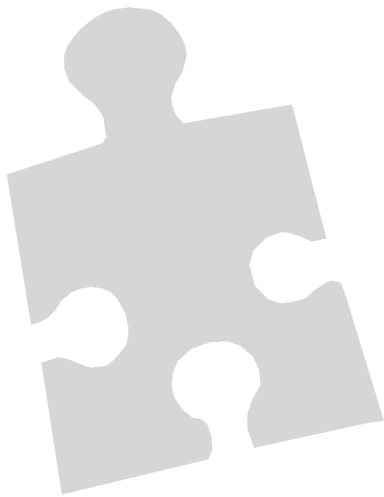


**One of a series of
People First
posters**

In Islington a unique advocacy project has been established, adopting a person-centred planning approach to supporting people with learning difficulties in the borough, as a direct result of the Campaign Network.

Stronger links have been established with the Greater London Authority at a strategic level.

There are now plans to establish a National Campaign Network.



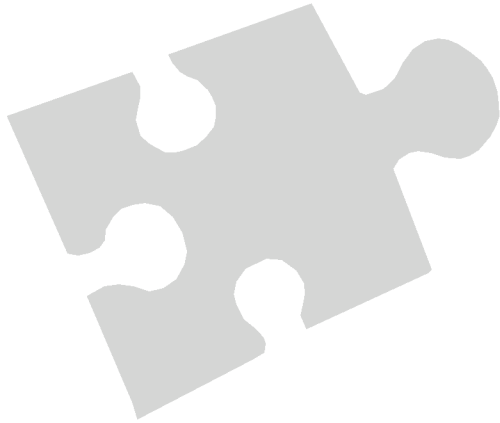
Other campaign work

People First took the lead in campaigning for changes to the Mental Capacity Bill. Several meetings were held with Lord Filkin, Parliamentary Under-Secretary of State, Department of Constitutional Affairs, who was responsible for progressing the Bill.

In the autumn of 2003, People First was invited to speak to the Parliamentary Joint Scrutiny Committee about its concerns. This was the first time ever that people with learning difficulties have been asked to speak to a Parliamentary committee.

People First was influential in the setting up of the 'I Decide' coalition. This is a group of organisations of disabled people who have now gained recognition as an appropriate

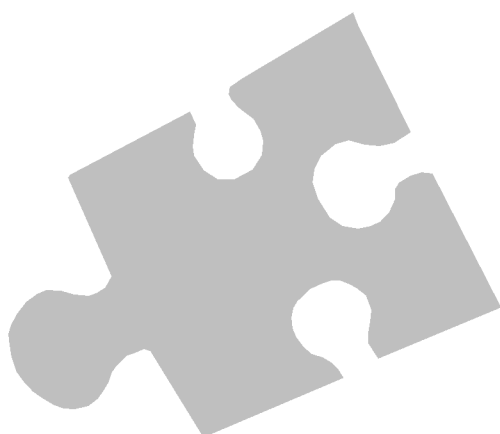
body which should be consulted by statutory and other agencies. Before this, the Making Decisions Alliance, an alliance of organisations *for* disabled people, was the only body that was being consulted. This is a big achievement.

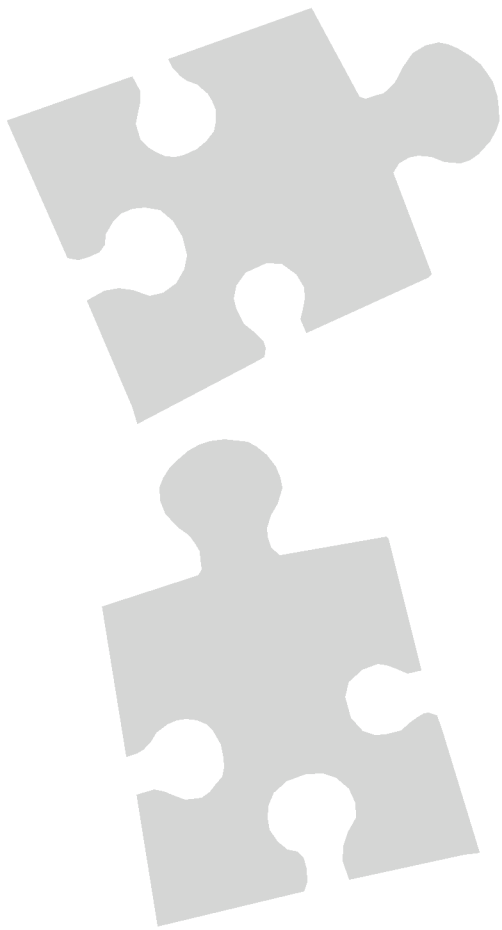


Campaigning saw improvements to the Mental Capacity Act. This included a shift in emphasis away from the assumption that disabled people cannot make decisions for themselves to a position where proof is needed as to why they are not able to make these decisions.

Other outcomes from the campaigning work include:

- 150 groups in London have gained from the improved resources and information developed on subjects such as direct payments, elections, how to make complaints, and campaigning for accessible information;
- Local government partnership boards now have people with learning difficulties involved in policymaking;
- People First were commissioned to produce a fully accessible version of Improving the Life Chances of Disabled People, a report published by the Prime Minister's Strategy Unit; (This report can





be downloaded from http://www.strategy.gov.uk/work_areas/disability/index.asp. This reference says that hard copies are no longer available).

- work with the Lord Chancellor's Department has encouraged them to make their leaflets and information more accessible. A good example is their leaflet on 'Making Decisions';
- the Department of Health produced a tool-kit for partnership boards. This taught them to work with inclusive ground rules, gave guidelines for presentations, and trained them to follow good practices in working with disabled people.

Accessible information

People First has also worked with a range of statutory and voluntary agencies to raise awareness about the need for accessible information (a requirement of the Disability Discrimination Act). It has produced good practice guidelines on making information accessible to people with learning difficulties, and three CD-ROMs providing a large picture bank.



Regional events and seminars

This was the lead area of work for BCODP. It was agreed that, as part of the programme, regional events and seminars should be organised to raise awareness of

CASE STUDY
**Somali Elderly
 and Disability
 Association
 Brent**

This association was founded in 2001 to assist disadvantaged people – older people, disabled people and women in particular. They meet regularly and have a small management committee of dedicated people.

It works with the local social services department to get help for the Somali community in north west London. Many of its members are refugees from war and suffer from trauma. The majority are disabled or are older people who need support. Volunteer interpreters provide assistance to its members and go along to appointments with social services, hospitals, housing and solicitors to help with communication.

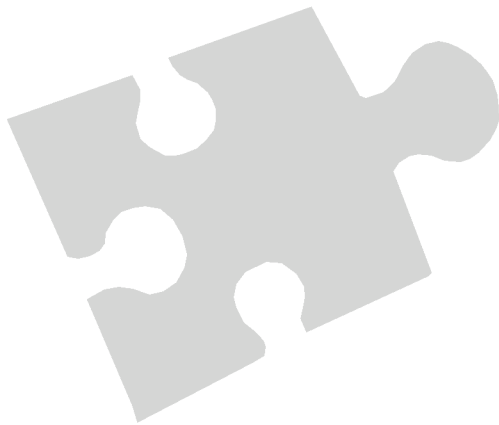
CUI provided help with fundraising. It has been difficult to raise funds for premises and to maintain its activities. The CUI Development Manager at GLAD worked with the management committee to develop their fundraising skills and encouraged them to attend the Forum meetings so that they could share their experience with other similar small groups. This has resulted in a much better understanding of what information the funders require and the organisation has had a number of successful applications for example from Fast Forward and Trust for London.

Links have now been made with Brent Council for Disabled People who are continuing to provide advice and support.



specific issues and to raise the profile of the *Count Us In* Programme.

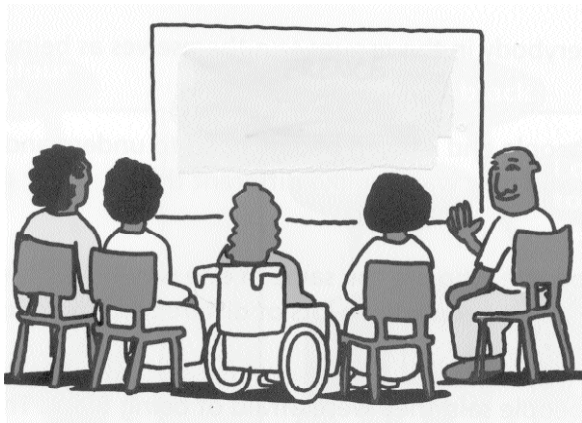
Organising these events and seminars was the main area of work for BCO DP with the support of GLAD and People First.



Four seminars and a launch event were organised during the first three years. Topics covered at these seminars included direct payments, sexuality, and refugees and asylum seekers. The seminars gave groups an opportunity to discuss these issues and to raise their awareness of the needs of specific people within their groups.

Consultancy support in Phase One

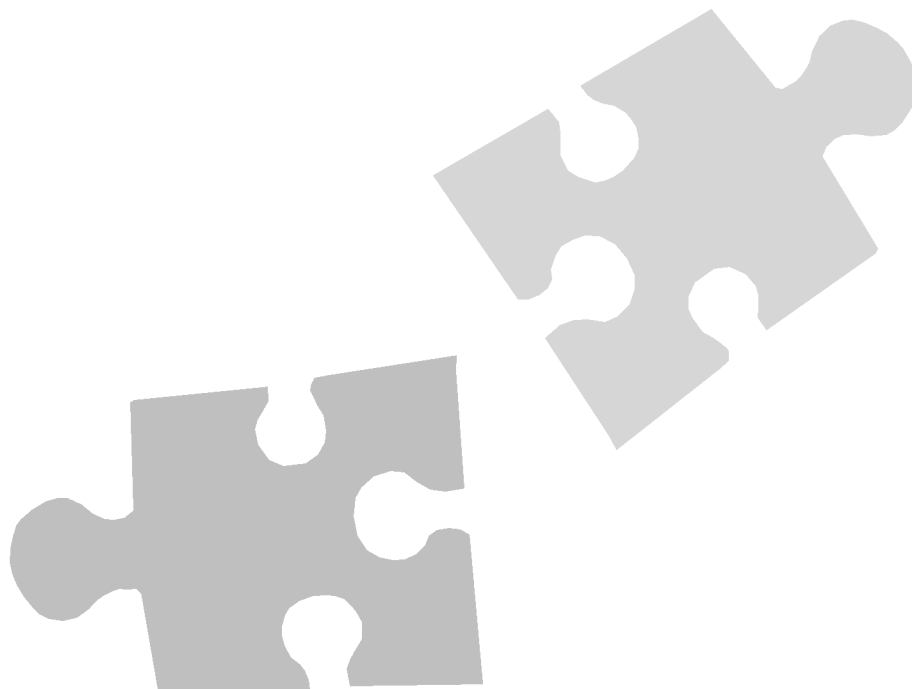
The Consultancy Fund was set up as part of the funding from City Parochial Foundation. The fund of £32,000 was set aside to provide specialist training and advice to small disability groups as needed.



The fund was to be managed by all three organisations but it took a long time to agree how the fund should be used, and it was frustrating that mid-way through the programme, no group had benefited from it.

Eventually, the terms were agreed and the fund was used to provide:

- training support to six groups of people with learning difficulties;
- project management training to 15 groups;
- support for a conference about *Count Us In* organised by People First;
- race and disability training for 20 councils of voluntary service and black voluntary sector organisations.



PART 3:
**Learning
from the
work**

Working together

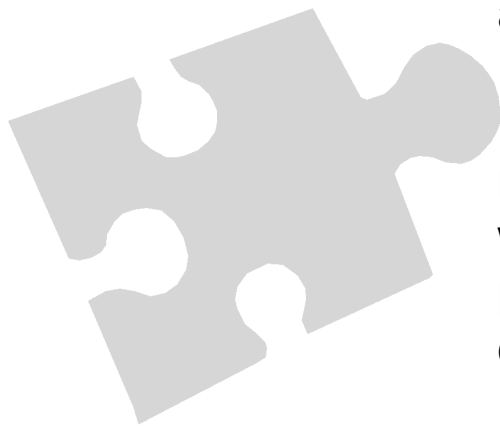
Count Us In was the first project on which GLAD, People First and BCODP had worked together and it took a long time to establish working relationships and good communication systems.

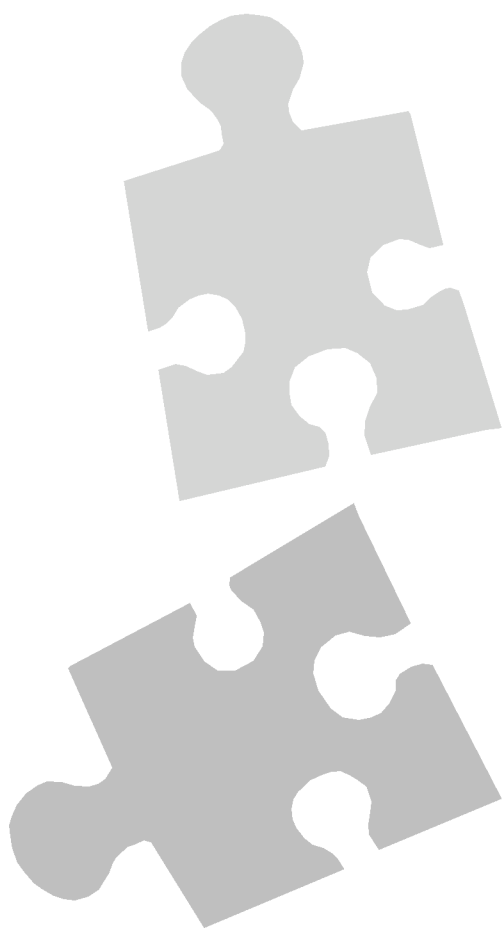
Assumptions were made at the start of the programme about the ability of each organisation to deliver the work, their understanding of the needs of bme disability organisations and how easy it would be for the organisations to work together.

GLAD and BCODP are both well-set up and respected organisations in the physical and sensory disability sector. People First, although quite new, had grown quickly into an umbrella organisation for the learning disability self-advocacy movement.

However, the divided nature of the disability movement and all of the other factors which were highlighted at the start of the programme, also affected these three organisations.

Each organisation has a different style of operating. For example, People First as a grassroots membership organisation, consults all its groups fully in decision-making. This can take time as many of the groups only meet once a month, whilst BCODP's and GLAD's directors take the





lead in decision-making and therefore are used to making quick decisions.

This sometimes meant that in the early part of phase one, GLAD and BCODP pushed ahead with decisions without waiting for People First. In Phase Two, matters improved as GLAD and People First developed their relationship and worked closer with each other, particularly towards the end of the programme, in their efforts to establish a pan-London disability forum.

One good thing was that everyone who was part of *Count Us In* was willing to learn from the others.

LESSON LEARNED

More time is needed at the start of a programme to develop relationships between the organisations.

Partnership working needs concerted effort by the whole organisation to make it work.

The leadership of the organisations involved need to understand the other partner organisations' different ways of working.

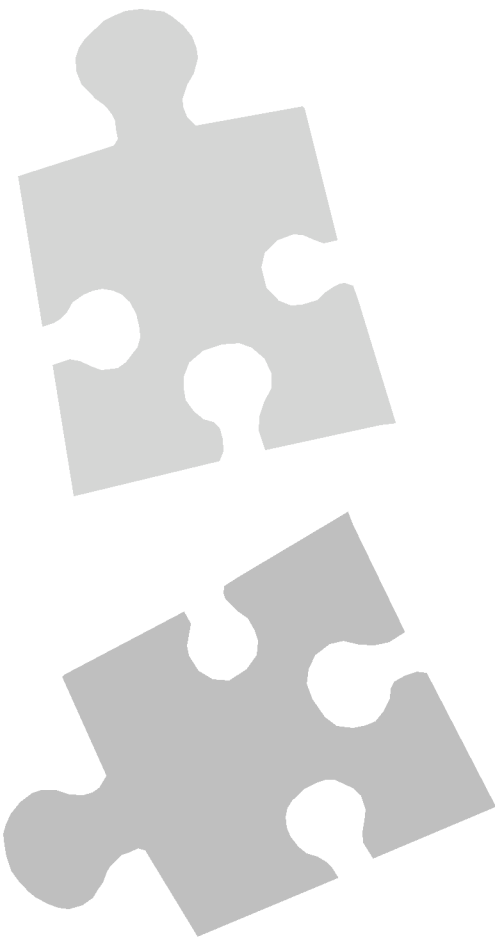
A common understanding of the social model of disability

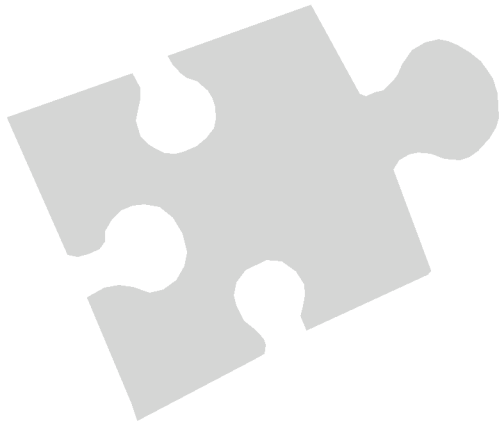
The social model of disability is based on the view that disabled people do not face disadvantage because of their impairments but because of the way society is organised. This includes all the barriers and discrimination disabled people face in their daily lives.

Discussions about the model have mainly focused on the experience of the majority population of disabled people and there has been little inclusion of the experience of black and minority ethnic disabled people in this debate.

This was challenged early on in the programme, particularly by the black disabled *Count Us In* workers at GLAD. They argued that the social model did not take into account the experience of being black and disabled.

People First acknowledged that they had not thought about this issue and set about doing research with their groups to find out about the experience of their black, ethnic minority, gay, lesbian and women members who are disabled. Several workshops were organised for members to discuss these issues. This led to a number of publications being produced.



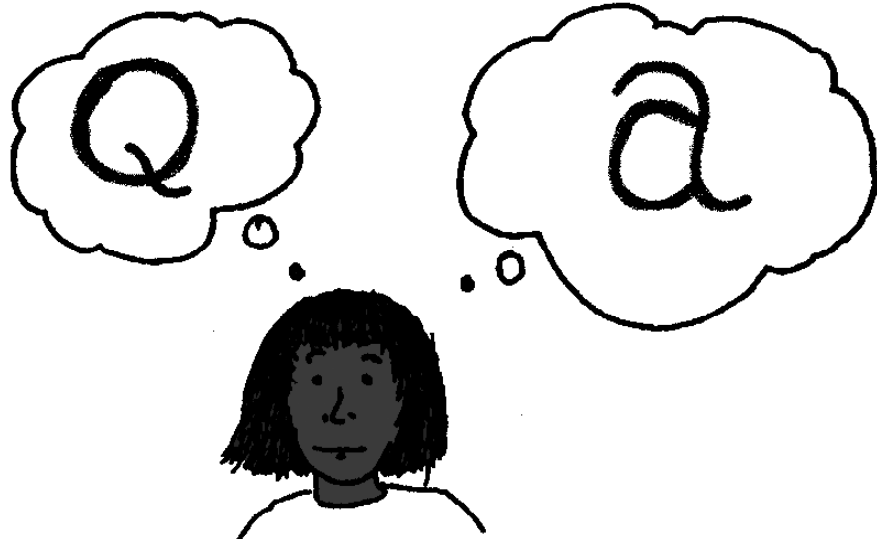


Research undertaken by Rachel Evans and Martin Banton of the Council of Disabled People in Warwickshire showed that many black and minority ethnic disabled people were falling between services for black people and services for disabled people. They also found that very few black and minority ethnic disabled people were involved in developing services:

“People felt it was impossible to separate out what they experienced as multiple oppression (e.g. for a black disabled woman, the experience of oppression based on race and impairment and gender). The failure of agencies to recognise the impact of multiple oppression left individual black disabled people unsure of where to turn.”

This issue was discussed from time to time at Policy and Development Committee meetings. Over the five years, there has been much greater insight and

understanding by all those involved in the programme that the social model needs to include the experiences of other groups of disabled people who may be discriminated against due to their race, culture, gender or sexuality.



LESSON LEARNED

The social model of disability needs to include and reflect the experience of black and minority ethnic disabled people and other minority groups, as well as the majority disabled population.

It is important that this experience is passed on to service providers and community/disability groups in a clear way. Services need to be set up to respond appropriately to these needs.

More contact is needed between disability groups and black and minority ethnic groups to improve understanding and to raise awareness of the needs of black and minority ethnic disabled people.

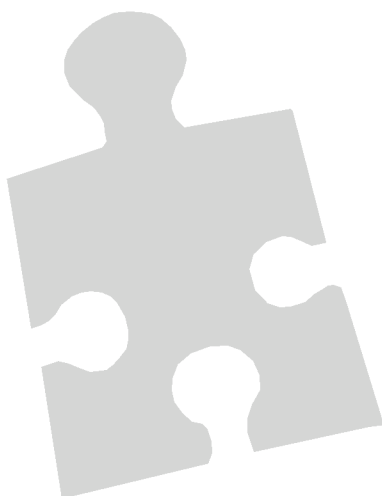
More opportunities are needed to empower black and minority ethnic disabled people to speak for themselves.

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.

Working with small black and minority ethnic disability groups

Initial contact with black and minority ethnic disability groups uncovered many problems that made it difficult for them to function and develop. These problems included:

- lack of resources;



- lack of staff – where they did have staff they were part-time and over-stretched;
- not enough access to relevant information about fundraising, training and support;
- feeling discriminated against – experience showed that many cultures hold very negative views towards disabled people;
- race is not a priority for the major disability organisations;
- disability is not a priority for black and minority ethnic organisations.

Overall the picture was one of hopelessness and they were sure that little would change as a result of *Count Us In*.

The GLAD *Count Us In* team had a difficult task ahead but the fact that they were black disabled workers themselves perhaps helped them to gain the confidence of the groups.



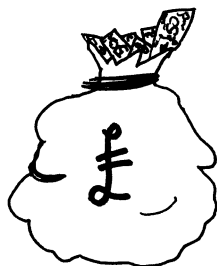
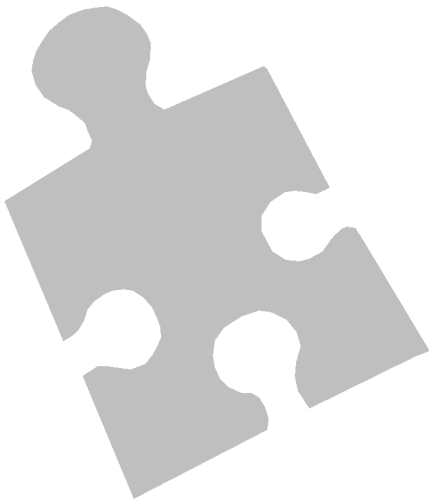
Progress was slow at first. This may have been partly due to the overwhelming needs of the groups but also due to the team's own lack of belief that they could change the situation. Although things improved, work with these small groups continued to be a lengthy process. This was partly due to the time it took to establish a relationship with the group, especially if they did not meet very often. It was also because of the multiple needs of the groups.

There were lots of new groups that approached *Count Us In* for advice and support. Groups that had previously been supported also continued to return to *Count Us In* when they faced difficulties. One of the main reasons for this was that many of the locally based capacity-building organisations, such as councils of voluntary service or black and minority ethnic specialist groups were not offering the intensive support that these small groups needed.

The number of applications to Trust for London from small black disability groups was very slow in the first three years.

There were many reasons for this. Some groups needed support and training before they were ready to make applications for funds. For example, managing money, strengthening management committees and agreeing priorities were areas where help was needed.

However, in the last year of the programme, applications have started to increase. Overall fifteen organisations have been supported with grants of £83,850. In addition, the Trust for London introduced a new accessible application form with easy words and pictures for people with learning difficulties.



LESSON LEARNED

Small bme disability groups have high needs and require intensive support.

It might have been better if work had been targeted on a smaller number of selected boroughs. Links between the capacity-building agencies, disability networks and small groups in that area could have been established, rather than trying to provide a service right across London. This could have provided models of good practice to be promoted to other boroughs.

Staff need to have a good range of skills to do this work, they also need a positive outlook to motivate groups. More training needs to be provided to improve the capacity of the staff team to undertake this work.

Funders need to adopt a proactive approach to encouraging applications from hard-to-reach groups such as small bme disability groups and to ensure that their application forms are accessible.

Only a limited amount of support is being provided to bme disability groups by capacity-building organisations. This could be due to a lack of awareness by some organisations about the specific needs of this sector or that such groups exist at all in their areas. Capacity-building organisations need to adopt a proactive approach to encouraging small bme disability groups to come forward to access their support. Funding needs to be made available so that these organisations can take this issue seriously.

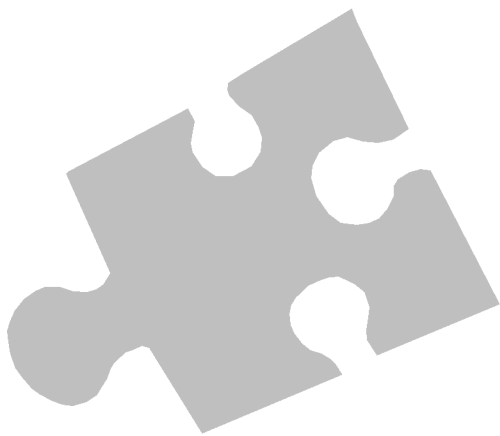
Work with second-tier organisations

Count Us In made contact with sixteen councils of voluntary service (CVSs) and three racial equality councils over the

timescale of the project.

The focus for the *Count Us In* development worker's links with CVSs and other capacity-building agencies continued on the same theme throughout the lifetime of *Count Us In*. This was to establish positive ways of encouraging CVSs to provide support to these groups.

This has been a difficult area of work. The main problem seems to be that with the growing emphasis on 'empowering' groups many CVSs workers expect groups to undertake most of the work themselves i.e. writing a draft application form which the worker will then advise them on. This can be a real barrier to many small disability groups. They need advice and support on how to develop their ideas and present their case.

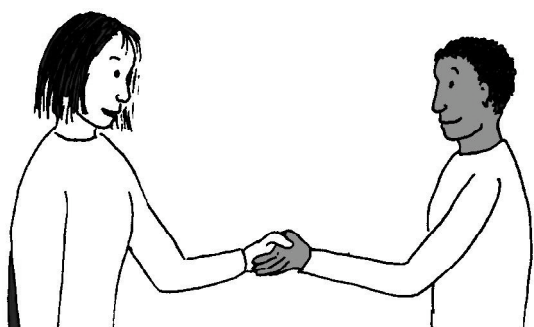


In addition, the knowledge and experience within some CVSs of dealing with the combination of race and disability issues is limited. Having said this, there were a number of good examples whereby staff within CVSs have developed partnerships with the local umbrella disability and learning difficulties organisations. This can provide them with more up-to-date knowledge of policies and procedures affecting service provision for disabled people.



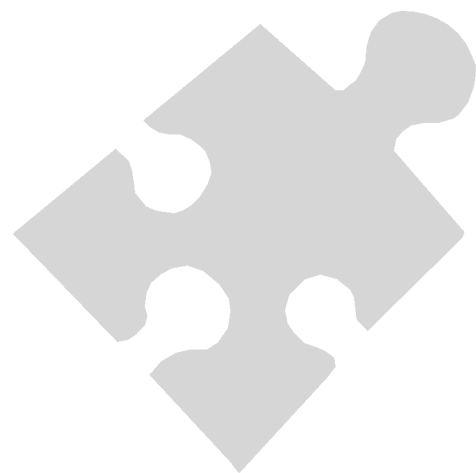
There were also examples of similar partnerships being formed with local racial equality councils to address some of the cultural and language issues that the CVSs need to be aware of in order to provide support to a group.

Work on establishing a black and minority ethnic disability forum for London



During the first phase of the project, the *Count Us In* Forum was established to provide mutual support and information-sharing opportunities for small black disability groups.

Although the forum initially took a long time to become established, towards the end of the third year it had gained momentum and had become much stronger. Discussions were held with the Black Londoners Forum to develop the Forum but did not lead anywhere. Unfortunately, efforts to establish the forum as an independent organisation to support groups and strengthen the voice of small black disability groups in London, did not move forward in year four, and it went into decline.



However, towards the end of 2004, the forum took on new members from the existing *Count Us In* groups. These new members were very task focused, ready to implement their newly obtained skills to plan

for the future and take ownership of the Forum. Another positive note was that bme members of People First are actively involved in this Forum. This provides some hope for the future.

Since the end of the *Count Us In* project, CPF has provided a further grant to support the development of the forum.

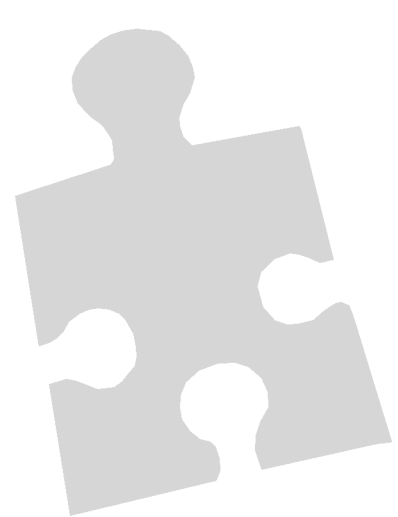
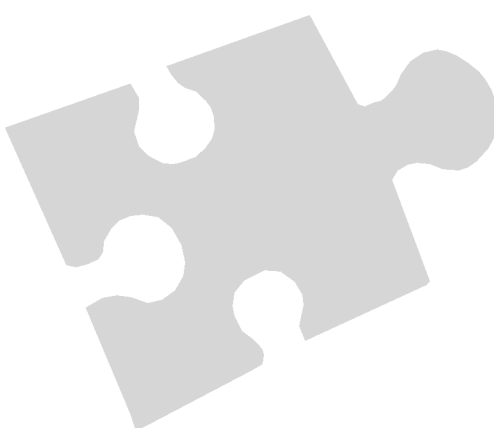
Support to self-advocacy groups

People First took the lead in developing this work and decided to focus on two main areas:

- developing good practice in self-advocacy groups;
- building an inclusive self-advocacy movement.

It soon became clear to People First that it was the support workers rather than people with learning difficulties who were controlling many 'so-called' self-advocacy groups.

This was a serious issue for People First and one which was only too familiar in their individual experiences. People with learning difficulties have to struggle to be in control of their own lives. Their research also showed that there were very few black and minority ethnic people with learning difficulties involved in these groups.



LESSON LEARNED

Establishing a pan-London voice for bme disabled Londoners is a big task. The Count Us In forum took a long time to set up. This is the first time that small groups of black and minority ethnic disability groups have come together and many have different and competing agendas.

The forum provides one of

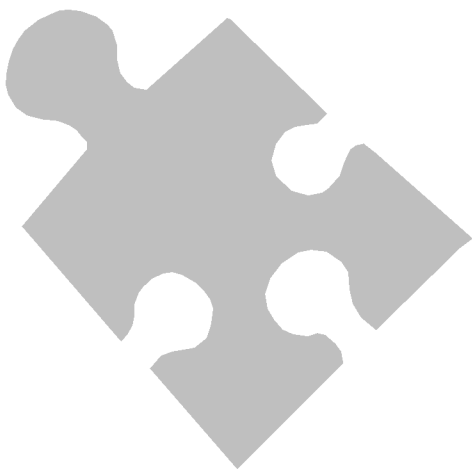
the few opportunities to bring together disability groups to work on a common interest;

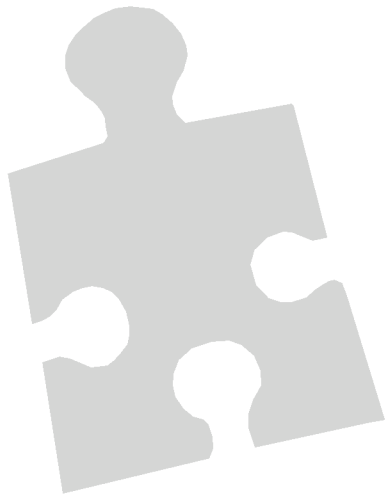
Stronger links need to be made with bme voluntary sector organisations involved in policy work so that they can share their skills and experience with the forum members. They can also learn about the needs of small bme disability groups.

People First decided to tackle these issues by providing training and consultancy support to self-advocacy groups and support workers.

It also decided to do some research on the social model and how it related to its work, and research into its groups to find out how many black, minority ethnic, gay and lesbian and women members belonged to each group.

The setting up of an advice shop was an important way for People First to provide training and support to self-advocacy groups.





The advice shop had a slow start. This was partly because it took longer than expected to find the right premises. There was also a delay in getting the access-to-work support for the advocacy worker. This experience led to People First providing advice to Access to Work – a government programme providing support for disabled people at work – on how it could make its application process more accessible.

Groups were also slow to make contact with the 'shop' and through further investigation the self-advocacy worker at People First

found that many of the groups did not meet very often which meant that keeping in contact was difficult.

It was also the case that the groups had a different understanding of being user-led (to that of People First) and that many were very dependent on their support workers.

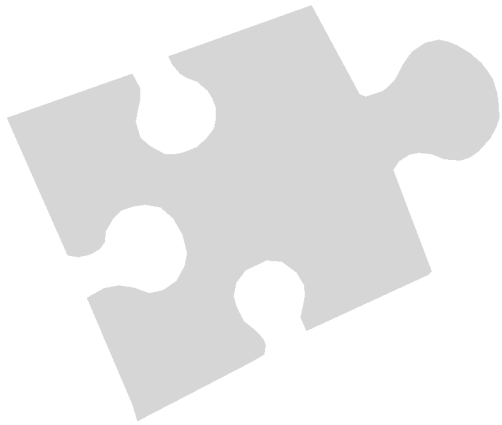
People First was keen to develop this work quickly and put in extra resources to take forward this work. An action plan was drawn up which included:

LESSON LEARNED

Intensive support is needed for self-advocacy groups to help them establish themselves as truly independent organisations and not to be reliant on support workers.

On-going training and advice is important to increase the skills of those involved in the group.

Making links between the groups helps them to support each other. The groups that now have stronger management committees help others to develop their skills.



- contacting people with learning difficulties directly;
- organising a conference to bring people together, including the pushed out groups;
- raising their concerns with support workers and providing training for them;
- raising the profile of People First and becoming more visible;
- delivering in-depth work with groups.

The situation greatly improved after this which led to a change in the way the support was offered.

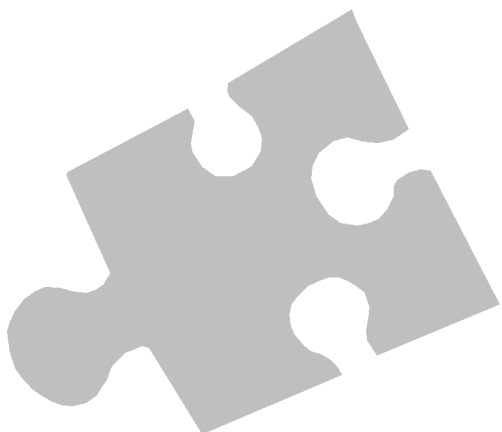
Campaigning and the law



During the past five years many changes have been made to legislation that affects black and minority ethnic disabled people. In 2000, for example, the Race Relations (Amendment) Act was enacted. The Disability Discrimination Act (DDA) 2005 which became law in April 2005 was just as important. The main impact of the DDA 2005 will be on the public sector, including local authorities, health authorities, and central government and public bodies.

From December 2006, all public sector bodies will have a duty:

- to “promote equality of opportunity for disabled people”;
- to promote the participation of disabled person in public life;



- to eliminate disability-related harassment;
- to eliminate unlawful discrimination;
- to produce an annual Disability Equality Scheme;
- to work in partnership with organisations of disabled people and with disabled service users.

LESSON LEARNED

Disabled people's groups need the skills and knowledge about their rights and how to campaign on issues and make their voices heard at both national and local level.

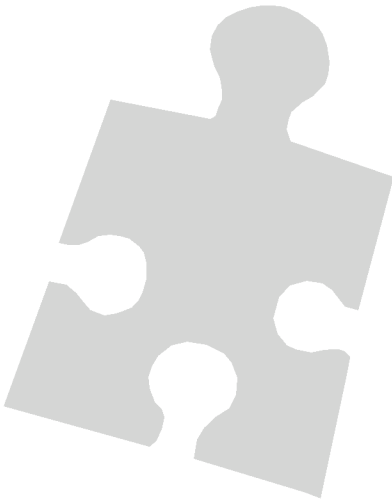
The work undertaken by People First has helped to show other groups how to do this work successfully. The tool kit it has produced is a useful way of sharing this information.

This work is not a high priority for a lot of disability groups because they are either involved in providing services as part of a contract with the local council or do not have the time to do this work.

For the first time, the focus is on organisational change, rather than individual adjustments as allowed for by the DDA 1995.

In addition, in 2003 the Government announced its intention to create a single commission to replace the three separate equality commissions – Commission for Racial Equality, the Disability Rights Commission and the Equal Opportunities Commission. This is likely to be in place in 2006 and will be called the Equality and Human Rights Commission.

The three organisations, GLAD, BCODP and People First had to take account of these laws and made changes to their policies and practices to make them more inclusive.



It is also noticeable that the needs of disabled people are much higher on the Government's agenda. Disability groups need to be in a position to speak about their needs and influence policies.

As already reported, work by People First to develop campaigning skills and to advocate changes in law and practice, helped achieve amendments to the Mental Capacity Bill.

Seminars

Count Us In was launched in May 2000 at the Resource Centre in Holloway Road. A further four seminars were held on direct payments, Accessible information, sexuality, and refugee and asylum seekers.

LESSON LEARNED

Seminars provide a good way to bring together organisations to focus on specific issues. However, they take a lot of planning and co-ordination (though in this project not everyone shared the workload evenly).

Finding accessible venues is a problem. Although many

organisations advertise their premises as being fully accessible, in practice many are unable to meet the needs of a large group of disabled people;

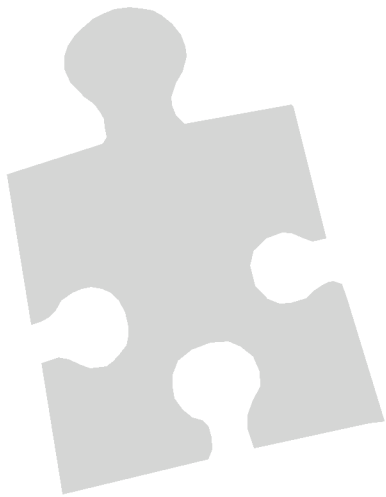
Presentations need to be shorter and more accessible. More time is needed to discuss the issues raised.



The seminars provided an ideal opportunity to raise the profile of *Count Us In* and to highlight the needs of bme disability groups in London.

Organisational issues

The *Count Us In* programme has helped all three organisations, as well as City Parochial Foundation and Trust for London to become more aware of the needs of small disability groups, black and minority ethnic groups and self-advocacy groups of people with learning difficulties in particular.



There is evidence that all three organisations have made efforts to include a wider range of people in their membership and to provide all of their information in an accessible format.

Staff changes had a significant impact on the programme. Many of the people involved in establishing the programme, Karen Edmunds (Director of GLAD), Richard Wood (Director of BCODP) and Alison Harker (Senior Grants Officer at CPF) left early on in the programme. Sara Bennett (Monitoring and Evaluation Officer at CPF) left after 18 months of the programme and Reg McLaughlin left his post as Director of GLAD early in 2004. Martin Jones (Director of Grants and Programmes) left in 2004 after a long period of sick leave.

LESSON LEARNED

When employing staff, disabled people's organisations need to be mindful that experience of being a disabled person itself is not enough. Employees need to have the skills and ability to do the work in order for the organisation to be effective.

Many disabled people, particularly those from bme communities, face many different forms of discrimination, which can negatively affect their employment potential. Organisations need to put in place a good training programme to ensure that

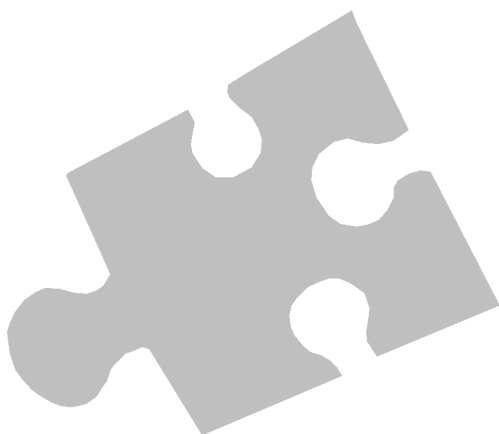
employees have the skills and knowledge to do the work. The cost of this training needs to be included in funding applications.

Skills and knowledge need to be shared within the organisation and not held by one person alone. This is crucial if the original aim and vision for the work is to continue.

If a project or programme has strategic aims it needs to be 'owned' by all levels within the organisation- management committee members, staff and volunteers

This has meant that new people have needed time to become familiar with the vision and aims of *Count Us In*. As a result of all these changes, progress in some areas have been much slower than expected and some aspects of the work have slipped.

Only three people have been involved in the



programme from the beginning to end – Andrew Lee (Director of People First), Jane Wilmot (CPF Trustee) and Manghanita Kempadoo (Consultant to the Foundation).

Some difficulties have also been experienced with the staffing at GLAD. The first development manager was unwell for long periods of time and eventually, the

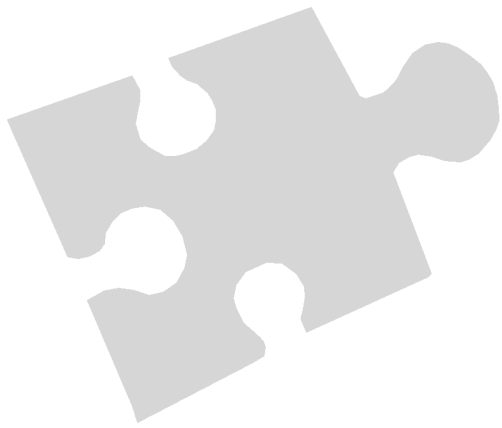
CASE STUDY

People First Black and Asian Group

People First Black and Asian Group
This group was formed as part of Newham People First. It is a mixture of several different nationalities with many of its members in residential care.

The group meets every second Thursday to explore black and Asian history or to watch a film and discuss issues afterwards. The barriers they face are:

- parents often feel ashamed of children with learning difficulties and want to keep their children at home, isolated;
- money is not available for the children or young people to get out and about;
- there are no real jobs for them – they are not trained and therefore work in low skilled jobs. They are often treated unfairly and not paid or rewarded properly for the work that they do;



development manager and development worker swapped roles. In addition, the development manager left before the end of the programme.

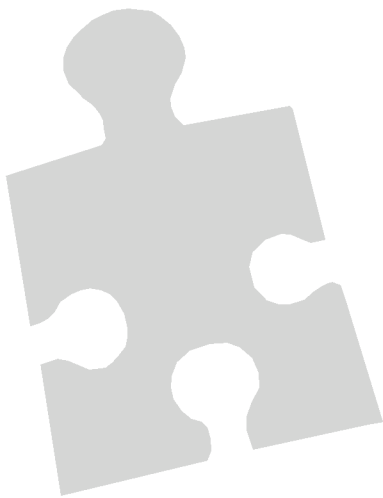
People First also had staffing difficulties towards the end of the programme when the Campaign Support Worker was on long-term sick leave. This meant that the

- they experience double discrimination – first as a person with learning difficulties and then as a black person;

The group have had help from Newham People First and People First (National) who showed them how to prepare and chair meetings. They attended training provided by the *Count Us In* development worker on user-led groups and are keen to learn office skills and communication skills.

The group wants to become independent eventually with its own management committee and a wider membership. It wants its members to be able to learn skills in a safe environment that will give them the chance to find real work. The group also wants to be able to influence what happens to black and Asian people with learning difficulties in Newham.

Campaign Network did not have as many meetings as it had originally planned. Out of this negative experience a much stronger Campaign Team has been established. The skills and knowledge is shared between the paid staff, volunteers and management committee members.



GLAD and People First adopted two different approaches to managing their *Count Us In* workers. For GLAD, *Count Us In* was a separate project within the organisation. At People First the aims of *Count Us In* became the aims of the organisation as a whole. The management committee of People First were highly involved in *Count Us In* which was not the case at GLAD. This meant that People First raised further funding from the Community Fund to expand the *Count Us In* programme nationally. It used its experience of working in London to help develop this work around the country.



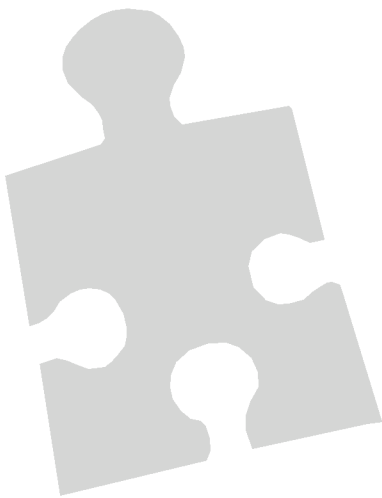
PART 4:

Conclusions and findings

- All organisations – community and voluntary sector, especially mainstream disability and bme organisations; statutory authorities; funders; and service providers should re-assess their policies and practices to make sure they are addressing the needs of bme disabled people and people with learning difficulties.
- Organisations making decisions which affect the lives of disabled people should make sure that all their documents are available in an accessible format (for example with easy words and pictures) and groups must be given enough time to comment during consultation.
- Practical programmes are needed to provide capacity-building support to small bme disability groups and groups of people with learning difficulties. In particular:
 - a) support and training to improve their campaigning skills in order to strengthen their voices;
 - b) a pan-London forum for bme groups of disabled people to discuss their needs, share experiences and strengthen their voice;
 - c) long-term and intense support at a local

level to help groups grow and develop. This cannot be left to one capacity-building organisation. We particularly welcome models of good practice such as local Councils of Voluntary Service working with borough disability organisations to meet the needs of small bme disability groups;

d) establishing better links between mainstream disability and bme organisations and small bme disability groups and groups of people with learning difficulties so that their skills and experience can be shared.



- GLAD has established a database of small bme disability groups in London. We recommend that this database continues to be developed as a resource for those working with small bme disability groups in London.
- Funders should have proactive approaches to encouraging applications from small bme disability and self-advocacy groups – application processes need to be straightforward and accessible.

APPENDIX 1:

Action points from People First

- information needs to be in easy to understand language for groups and individuals to have an equal chance of securing funding and services;



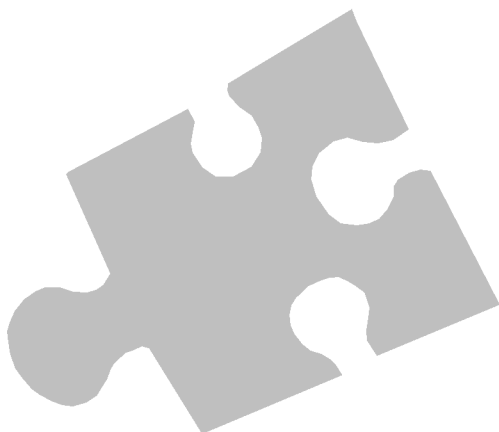
- user/self-advocacy groups should get training for members in equal opportunities which should include race, faith, gender, gay, lesbian, bisexual and transgender issues, as well as disability. Just because groups are fighting for the rights of disabled people does not necessarily mean that members understand the rights or needs of other groups in society;

- talk to bme disabled people about their experience and their needs – don't assume you know what these are;

- if you are intending to include bme disabled people in your activities, don't expect people to join a white-led group. You may need to set up a new group/service to meet their needs;

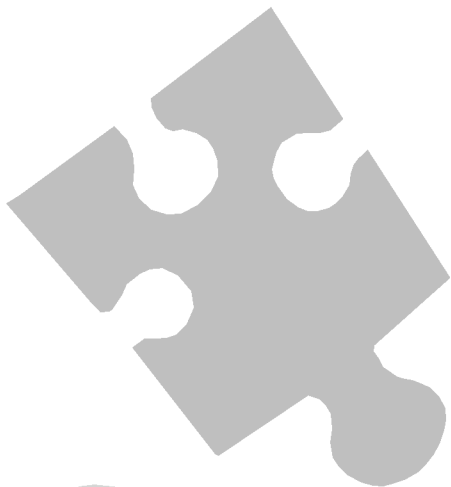


- if you are looking for a worker for your group, make sure you employ someone with knowledge and experience of the social model of disability.



APPENDIX 2: **Glossary**

- **self-advocacy:** helping people to make their own case about their needs and wishes
- **capacity building:** making sure organisations have adequate resources, and the people involved have proper training to enable them to do their jobs to the best of their ability
- **bme:** black and minority ethnic – people who come from backgrounds or live in communities which have their roots overseas. It includes people who have lived here all their lives, as well as more recent migrants.
- **proactive:** taking the initiative rather than simply making changes as things happen.



Acknowledgments

The authors wish to thank everyone who contributed to this final report. In particular to:

The many small disability groups and voluntary organisations who were willing to share their views with us.

All trustees and staff at City Parochial Foundation for their support throughout the programme and to those who were particularly involved including:

- **Jane Wilmot** (*Trustee*)
- **Bharat Mehta** (*Clerk to the Trustees*)
- **Mubin Haq** (*Principal Officer Grants*) and ex-staff members
- **Martin Jones** (*Director of Grants and Programmes until 2004,*)
- **Sara Bennett** (*Monitoring and Evaluation Officer until 2001*) and
- **Alison Harker** (*Senior Grants Officer until 2002*).

In addition, our thanks go to:

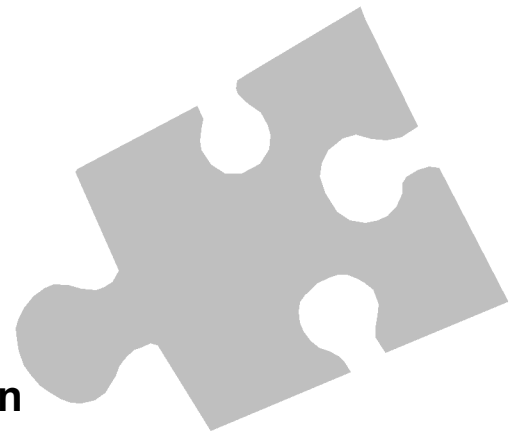
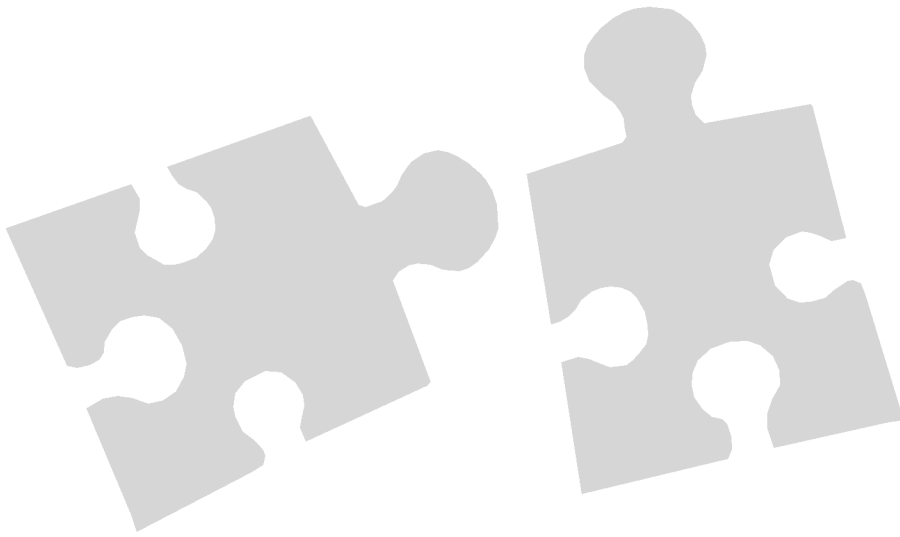
- **Baroness Wilkins** (*Member of the Joint Scrutiny Panel on the Mental Capacity Bill, House of Lords*)
- **Tara Flood** (*Scope*)
- **Dave Morris** (*Disability Officer, Greater London Authority*)
- **Dr. Ossie Stuart**

Trustees, staff and volunteers from the three funded organisations:

- **Greater London Action on Disability** (*GLAD*)
- **People First**
- **British Council of Disabled People** (*BCODP*)

Illustrations provided by People First

Editing and photography:
Chris Bazlinton
Design: Ray Eden



City Parochial Foundation

E-mail: info@cityparochial.org.uk

Trust for London

E-mail: trustforlondon@cityparochial.org.uk

6 Middle Street
London EC1A 7PH

Telephone: 020 7606 6145 Fax: 020 7600 1866
Website: www.cityparochial.org.uk

Charity Registration Numbers:
City Parochial Foundation 205629
Trust for London 294710