

Improving support for black disabled people

Lessons from community organisations on making change happen

Becca Singh

A review of four community organisations providing support to black disabled people.

This study reviews the JRF's *Making Change Happen* programme, which provided a year's funding to four grassroots development organisations with a track record in providing support to black disabled people. The report sets out the learning that emerged from the four development projects. It includes:

- overviews of the four development projects;
- learning and common themes, with boxed illustrations from the projects;
- detailed case studies from two of the projects;
- practical pointers and suggestions for voluntary and community organisations wishing to improve support to black and minority ethnic disabled people; and some questions for funders and service providers to consider.

The report will be of interest to both policy makers and practitioners in the field.



**JOSEPH ROWNTREE
FOUNDATION**



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Contents

Acknowledgements	vii
1 Introduction and context	1
A programme of research and development	1
What does research tell us about the experiences of black disabled people?	3
Legislative and policy context, including recent developments	5
Summary	7
2 Overview of the four development projects in the <i>Making Change Happen</i> programme	8
<i>Helping Each Other, Helping Ourselves</i> , run by <i>Tassibee</i> in Rotherham	8
<i>ROOTS</i> , run by <i>People in Action</i> in Leeds	10
Service Plus, run by <i>ISCOM</i> (International Somali Community Trust), London Borough of Hackney	12
Waltham Forest Disabled People's and Carers' Partnership, run by <i>EQUALITIES</i> , London Borough of Waltham Forest	14
3 Emerging lessons from four grass-roots projects	17
Recognising and celebrating multiple identities	17
Faith and religion	22
Language	22
Challenging myths and prejudices	23
Shared and separate spaces for disabled people and carers	24
Building individual and organisational capacities ...	26
... Through increasing the number of skilled volunteers and workers	26
... Through training	26
... Through networking	28
... Through data collection and monitoring	28

Paying project participants and volunteers	29
Meeting people's basic needs	30
Working under difficult circumstances	31
Supportive allies	32
Funding	33
Summary	35
4 Case study 1 <i>ROOTS</i>: black people with learning difficulties training service providers	36
Introduction	36
Aims	37
Timetable	37
Process	38
What are the training sessions for service providers and organisations like?	40
Outcomes	41
Learning from this project	43
5 Case study 2 <i>Helping Each Other, Helping Ourselves</i>: self-help groups supporting Pakistani Muslim women	44
Introduction	44
Aims	45
Timetable	45
Process	46
Outcomes	48
Learning from this project	51
6 Summary and pointers for practical action	53
Some practical pointers for any organisation working to improve support for black disabled people	56
Questions for organisations, funders and service providers	58
References	66
Appendix: Methods	68

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1 Introduction and context

This chapter introduces the Joseph Rowntree Foundation's *Making Change Happen* programme, which aimed to generate practical and positive information on how to improve support to black disabled people. It also includes a short summary of 'what we know from research' and relevant policy developments.

A programme of research and development

Over the past decade, the Joseph Rowntree Foundation (JRF) has supported several research projects about the lives and experiences of black disabled people, children and their families in the UK. Some of the main findings from this work have recently been summarised in a short report for the Foundation on 'Experiencing ethnicity: discrimination and service provision' (Chahal, 2004; see below).

The most salient responses to this research were that:

- most research tended to focus on poor practice rather than good practice (researchers reported difficulties finding enough good-practice examples)
- there was a demand for action rather than yet more research.

These views were commonly held by black disabled people wanting support as well as professionals from statutory and voluntary organisations providing services for this client group.

Improving support for black disabled people

Black communities are tired of taking part in research that asks them what they want from services, only to find nothing happens until five years later when they are asked the same questions over again.

(Flynn, 2002)

On the basis of this evidence, the Foundation set up *Making Change Happen*, a time-limited programme that provided 12 months' funding to four grass-roots development organisations. These had a track record in providing support to black disabled people. This focus potentially offered more positive and practical learning to others hoping to improve support to this diverse and often disadvantaged group.

To make this learning available to a wider audience, the Foundation funded a small additional project: *Learning the Lessons*. It is this project that forms the basis for this report.

Learning the Lessons was designed to work alongside the development projects to identify common themes and useful lessons for others. It was not intended to assess the intrinsic worth of each project, nor to evaluate their success in meeting their objectives, except where lessons could be learned to improve support. Projects in the *Making Change Happen* programme were required to participate in *Learning the Lessons* as part of their funding agreement with JRF. They felt that it was useful to know that someone else was recording the project, without making additional demands on staff. They also found it helpful to receive feedback from the researcher at different times during the project. *Learning the Lessons* used observation, documentary evidence, participation and interviews at different stages of each development project. The illustrations in this report reflect the variety in quality and quantity of data collected.

This report sets out the learning that emerged from the four development projects. It contains:

- overviews of the four development projects
- learning and common themes, with boxed illustrations from the projects
- detailed case studies from two of the projects
- practical pointers and suggestions for voluntary and community organisations wishing to improve support to black disabled people; and some questions for funders and service providers to consider.

Throughout the report, I have used the term 'black disabled people' in the same context that JRF used it in the call for proposals that led to these development projects. This uses the Social Model of Disability to describe a disabled person as someone with impairment, learning difficulty or mental health difficulty who is disabled by barriers in society. 'Black' describes a person from a minority ethnic community or with a minority ethnic racial identity who may experience discrimination based on the colour of their skin or their cultural heritage.

What does research tell us about the experiences of black disabled people?

A recent summary report for the Joseph Rowntree Foundation draws together some of the main findings from the Foundation's programme of research on and with black disabled people, children and their families (Chahal, 2004).

Improving support for black disabled people ---

Particular findings include:

- black service users felt mainstream services were often inappropriate for their needs and that services made assumptions based on stereotypes and prejudice about what the needs of these users might be or what they might want to access
- the experience of racial discrimination and prejudice in mainstream service provision often meant that minority ethnic users requested specialist, culturally competent services
- there were few black staff in mainstream services and some of the services had made little attempt to change this
- there was a general desire for more information about services and entitlements from service providers. For example, very few disabled people had any knowledge of direct payment schemes (which make cash payments to individuals to purchase personal assistance, chosen and controlled by them)
- religious and cultural identity was very important to many people from minority ethnic communities but it was rarely responded to by mainstream service providers
- common myths about informal family networks looking after each other should not be taken for granted. Although informal support is available in certain circumstances, this cannot be relied on
- people sometimes experienced discrimination and prejudice within their own community and faith groups
- the differences between the experiences of men and women were often sharper than the differences between different ethnic groups.

Evidence from research funded by JRF and others also indicates that:

- black disabled people have multiple identities and support needs. Their experiences have been described as ‘double’ or ‘triple’ discrimination (e.g. as a black disabled woman) and as ‘multiple oppression’. Services aiming to support black disabled people must recognise the complexity of identity and subsequent support needs from the start in order to be effective
- black disabled people routinely fall between organisations and services focusing on disabled people and those focusing on minority ethnic communities
- disabled children and adults are frequently faced with low expectations of what they can do, and this in turn reduces their own aspirations, self-confidence and expectations
- disabled people and their families want support that is timely, appropriate, accessible and flexible, designed to meet their own needs and lifestyles, and delivered by people who ask them what their needs are and how best to meet these. Often, community organisations are better placed to meet these needs.

Legislative and policy context, including recent developments

Several recent policy developments have the potential to offer a more supportive framework for improving services to black disabled people and recognising the experience of multiple discrimination.

Improving support for black disabled people

Examples of relevant policy developments include:

- *Improving the Life Chances of Disabled People* (Prime Minister's Strategy Unit, 2005): a joint report from the Prime Minister's Strategy Unit with Department of Work and Pensions, Department of Health, Department for Education and Skills and Office of the Deputy Prime Minister
- *Fairness for All: A New Commission for Equality and Human Rights* (Department of Trade and Industry, 2004) announced the Government's plans to bring together the work of the three existing equality commissions (Equal Opportunities Commission, Commission for Racial Equality and Disability Rights Commission)
- Draft Disability Discrimination Bill (2005), which will amend the Disability Discrimination Act (1995) and introduce a wide range of measures recommended by the Disability Rights Taskforce, including a new duty placed on the public sector to 'promote disability equality'. This will bring disability legislation in line with the duties outlined in the Race Relations (Amendment) Act (2000)
- *Learning Difficulties and Ethnicity: A Framework for Action* (Department of Health, 2004) takes forward the work of the Sub-group on Ethnicity of the Learning Disability Task Force
- *Delivering Race Equality in Mental Health Care: An Action Plan for Reform Inside and Outside Services* (Department of Health, 2005) sets out a five-year action plan for reducing inequalities in black patients' access to, experience of and outcomes from mental health services
- *Inside Outside: Improving Mental Health Services for Black and Minority Ethnic Communities in England* (Department of

Health, 2003) sets out the Department of Health's plans to: reduce and eliminate ethnic inequalities in mental health service experience and outcome, including developing the cultural capability of mental health services; and engaging the community through community development workers

- *A New Vision for Adult Social Care* (Wistow, 2004) reported the results of a survey undertaken for the Department of Health by the Social Care Institute of Excellence, which will feed into a forthcoming Green Paper on the future of adult social care.

Summary

Evidence from research suggests inappropriate, under-resourced services, resulting in high levels of unmet need among black disabled people in Britain. There is much that still needs to change. Recent and forthcoming legislative and policy developments will provide a much-needed supportive framework within which such changes *could* take place. But, as always, the question will be: what enforceable steps (with appropriate resources) will be taken to ensure that black disabled people benefit from such changes as much as white disabled people and their families?

The findings of this report highlight concerns and strategies about equal access for black disabled people. Both community organisations and services users are involved in improving support services at the moment, so it is important that they will be empowered to use available resources and take a central role in delivering the Government's future vision. Failure to build on their expertise, experience and community links would represent a lost opportunity to make change happen.

2 Overview of the four development projects in the *Making Change Happen* programme

This chapter sets out the aims of each project, with a brief description of the processes where possible. This information has been taken mainly from the projects' proposals, which were accepted by the JRF in December 2002 or March 2003. This is supplemented or adapted by details of what actually happened. Two of the projects (*ROOTS* and the *Tassibee* project) provided very rich and varied data, enabling two more detailed case studies, which can be found later in the report.

***Helping Each Other, Helping Ourselves*, run by *Tassibee* in Rotherham**

Aims

- To strengthen and develop the capacity of *Tassibee* to work with women with long-term mental health problems, using self-help and empowerment principles.
- To run two self-help groups along these lines.
- To reduce the stigma around mental health problems between the women involved in the project, with the longer-term aim of reducing stigmatising attitudes within users of *Tassibee* generally.

Background

Tassibee started as a prayer group for Pakistani Muslim women in 1993. It now runs a weekly open luncheon and prayer group, and a range of training, support and social activities to meet the needs of isolated, variously excluded women, many of whom are first-generation migrants. The ethos of the organisation is geared towards addressing barriers, building on strengths and enabling change in the lives of the Pakistani Muslim women in Rotherham. Process and inclusivity are recognised as key issues; the process of how the group works together and with external organisations is seen as equally important to the outcome.

A need for self-help groups was identified in research (Smith, 2001) conducted for the organisation by one of its long-standing allies.

Process

A number of Pakistani Muslim women was trained to develop self-help groups, using life-story work as a vehicle for empowerment and change. These women were all known to *Tassibee* already, as volunteers, sessional or outreach workers, and all had direct experience of mental health difficulties.

Two self-help groups were then run, one for older women and one for younger mothers. Using a variety of social and leisure activities alongside life-story work, these groups helped individual women to build on their strengths and become more assertive and confident. Sharing life stories gave the women opportunities to learn from each other and share coping mechanisms.

Outcomes

Women who were on the *Tassibee* project have significantly improved self-confidence and are more assertive. More of them now use public transport and go out alone into Rotherham. Several of the facilitators have gone on to further education courses or employment elsewhere. *Tassibee* has decided to focus on finding long-term funding for a volunteer support worker in order to reduce the burden on the co-ordinator and administrative worker.

ROOTS, run by People in Action in Leeds

Aims

- To use direct experience, shared learning and good-practice examples to promote positive change in the attitudes of staff working for local service providers and the culture of other organisations (including the Leeds Learning Disability Partnership Board).
- To help direct this change to provide appropriate support for African Caribbean people with learning difficulties.

Background

People in Action has empowered people with learning difficulties through leisure and social opportunities since 1983. It has a multicultural staff team. *People in Action* has significant experience of service user involvement, provision of information and advice, project management, person-centred planning, leisure and arts opportunities, community networks and

Overview of the four development projects

partnership working. It has been involved with various developments since 1991 to improve support to African Caribbean people with learning difficulties. There is a steering group in Chapeltown (an area of Leeds with a large African Caribbean population), which directs the work that *People in Action* does in this locality. In July 2002, the steering group drew a PATH (an inclusive planning tool) to plan how it would work towards its dream over the following year. This PATH included the *ROOTS* project as part of its target for 2003.

Process

A small-scale audit carried out at the start provided a benchmark for current service provision. This audit also identified organisations that wanted to work with *ROOTS* on a more intensive basis.

A team of six African Caribbean people with learning difficulties was appointed. They explored their culture, heritage and personal life stories using different arts media with support from experienced support workers and a creative arts worker. A 'taster' day was held for potential participating organisations. They were then offered presentations developed and delivered by the team, followed by a training day using the PATH planning tool. Shorter training packages were also available. All of this work was linked to the PATH drawn up by the Chapeltown Steering Group in 2002, updated in 2003 and 2004.

A participative conference raised the profile of the work locally, as well as developing wider networks and sharing lessons learned. The conference was chaired and presented by the team of African Caribbean people with learning difficulties.

Outcomes

Several service providers in Leeds who received training from the *ROOTS* team have developed their practices to take on board the issues raised. *ROOTS* has continued as a training provider and has received some funding to support it to become a Social Enterprise.

Service Plus, run by *ISCOM* (International Somali Community Trust), London Borough of Hackney

Aims

- To establish a forum for disabled Somali-speaking people living in the area.
- To co-ordinate and develop a number of existing services for disabled Somali-speaking people.
- To link the beneficiaries of these services into other disability and mainstream provision.
- To help local service planners understand the demography of local asylum-seeker and refugee populations, identify their needs and inform their services.

Background

ISCOM provides home care services, advocacy, informal carers' home sitting, befriending, interpreting and translating services for the Somali-speaking population in Hackney. Many

Overview of the four development projects

of this community are recent arrivals to the UK; many are refugees from the civil war in the 1990s. The project was developed from needs expressed by disabled people within the Somali community.

This project aimed to bring about change through empowering service users of *ISCOM* to voice their opinions of the services. It provided assistance to carers and helped identify their support needs, as well as offering a forum for the voice of disabled people using *ISCOM*'s services to be heard. It aimed to provide an example for other minority and refugee communities on engaging with mainstream services on disability issues.

The project built on services that *ISCOM* already provided and centred on a community centre where many people interact on a regular basis.

Process

The project worker (the first full-time worker to be employed by *ISCOM*) met with other disability groups, visited each disabled service user on a regular basis and developed systems for recording and monitoring their needs. Much of the work concentrated on individual advocacy, but, through careful record keeping, the project worker was able to bring to forum meetings issues to discuss that were genuine concerns without individuals being identified.

The forum proved to be a social event, which centred on food, with the addition of educational speakers and frank discussions. Social activities, such as trips out of London, were organised to offer to forum members as payment in kind for

Improving support for black disabled people

helping to shape *ISCOM*'s services. Towards the end of the project, a Disability Equality Training Day was held at one of the forum meetings and this proved very popular and useful.

Outcomes

Several individual disabled Somali people had their lives significantly improved by the project worker acting as an advocate for them. This has included moving into a more accessible flat, getting registered with a GP and claiming benefits that they are entitled to. *ISCOM* as an organisation is much more aware of the issues involved in disability equality because of the specific training. The work done during the Service Plus project to establish recording and monitoring systems provided *ISCOM* with the evidence and systems they needed to secure funding for two part-time advocacy workers.

Waltham Forest Disabled People's and Carers' Partnership, run by *EQUALITIES*, London Borough of Waltham Forest

Aims

- To establish a partnership of black disabled people and their organisations in Waltham Forest.
- To develop the partnership into a vehicle that has a strong collective voice in the community in order to influence local policy development and service provision.

Background

The Partnership was identified as a vitally needed resource within the area used to influence service provision and policy development, and give black disabled people a safe space to voice issues and concerns. The local authority had expressed interest in such a body, but was unable to finance it because of their funding structures.

The Partnership aimed to bring together both voluntary groups and statutory bodies providing services to black disabled people and individual people with long-term conditions. The project needed to overcome a disillusioned voluntary sector and overburdened organisations.

Process

The project started with a survey to determine levels of interest and commitment to the project within the borough. As a result of this survey, *EQUALITIES* decided to involve black carers as well as disabled people because the carers' view was that their cultural needs were not being fully met by the local authority. It became obvious that smaller voluntary sector organisations found it difficult to send representatives because of a lack of resources. Those who attended meetings organised by *EQUALITIES* came on an individual basis in their own time.

At this time, the Local Strategic Partnership (LSP) and the Community Empowerment Network (CEN) were formed. *EQUALITIES*' chief executive (who was working on the JRF-funded project) was chair of the CEN and a representative on the LSP. *EQUALITIES* felt that there was considerable potential to bring about change using these newly created strategic bodies and the structures within them.

Improving support for black disabled people

However, both these approaches faltered. Despite *EQUALITIES*' representatives actively working on this agenda, they felt that the LSP was ineffectual and unwilling to develop a disabled people's partnership. *EQUALITIES* has since withdrawn its involvement from both.

EQUALITIES was working under difficult circumstances; the local authority had been placed under Special Measures (2001/02), which led to significant personnel changes and a chaotic structure with which to work. *EQUALITIES*' workers found it mystifying, saddening and frustrating that it proved so difficult to influence these bodies, and to secure a specific space for black disabled people and carers on these local strategic bodies.

Outcomes

EQUALITIES identified key strategic bodies to work with to improve support for black disabled people and carers. It learned that establishing a network of underfunded, disparate black voluntary sector organisations is not necessarily the most successful way to change services. National lobbying proved more productive to increase the voice of black disabled people and carers locally.

3 Emerging lessons from four grass-roots projects

This chapter sets out the main learning points from the four development projects (Chapter 2 provides an overview of each project). The emerging lessons cover a wide range of topics, from techniques used by the projects to wider issues such as paying participants and working in more than one language. Some topics are specific to work with black disabled people; others can be applied more generally.

Recognising and celebrating multiple identities

Central to all projects working to improve support for black disabled people is the issue of identity. Often, black disabled people slip between support for black people and support for disabled people. Disability services can be culturally inappropriate; services for black people can be inaccessible to disabled people.

A person's identity is not something that can be split up into parts to provide support. One can't ignore part of one's identity while dealing with another aspect. Martin Banton (2003) summed this up:

For me, one of the most powerful statements from the people I interviewed when I did the research was from a Black disabled woman: 'As a Black woman, I can't say "Well I'll deal with my gender today and my race tomorrow", because I have to deal with it as one person, you know, and the same can be said of

disabled people and lesbians and gays, black disabled people, you know whatever combination of oppression.'

(Banton, 2003, p. 3)

Several projects found ways to recognise and bring to the fore multiple identities and experiences of 'double discrimination' or 'multiple oppression'. The projects used a variety of techniques to do this.

Sharing personal life stories

Sharing life stories was important in three of the projects: those run by *Tassibee*, *ROOTS* and, to a lesser extent, *ISCOM*.

Black disabled people can be isolated; sharing their life stories in a safe space can help to overcome this sense of isolation, enabling people to understand that some of the issues are part of wider society, not necessarily directed personally at them.

Both *ISCOM* and *Tassibee* described a tradition of older people expecting younger people to listen and learn from them; the development projects helped to break down those barriers and allow people from different generations to learn from each other.

- *Tassibee project*: younger women and older women found that they were able to learn from each other as they shared life stories in the training programme at the start of *Helping Each Other, Helping Ourselves*. Despite the age differences, and societal changes in the UK, the women's experiences of leaving rural villages in Pakistan and coming to an urban area in Yorkshire were very similar. They were able to share coping mechanisms.

Continued

Emerging lessons from four grass-roots projects

- *ISCOM*: Somali culture has an oral tradition. The Somali language only began to be written down towards the end of the twentieth century, so all Somali wisdom has been passed on through story telling, poems and songs from one generation to another. Using life stories in the project helped intergenerational learning.
- *ROOTS*: the life stories of team members contained significant experience of being bullied. Sharing these was a good way to understand the impact of discrimination and prejudice on their lives. They were then able to use their life stories in delivering training to show service providers how society and systems had been failing them.

Learning about identity, culture and heritage

The projects run by *ROOTS*, *ISCOM* and *Tassibee* all provided different opportunities and support for both workers and participants to learn about and celebrate their own and other people's identities and different cultures. For example, many of the team members in *ROOTS* had missed out on learning about their cultural heritage and history as black people. For some, this was because they had grown up away from their family or community, or had attended schools that did not provide this sort of education. Projects also found it useful to ensure that participants and workers were aware of current debates, policies and good practice.

Blending new ideas and activities with valued traditions

Three of the projects explicitly used concepts, methods and ideas taken from different cultures to achieve the aims of the project. Where ideas and methods were new to the community,

Improving support for black disabled people

they were introduced sensitively and with care. This relied on the integrity of the workers involved, and their ability to introduce a new idea or activity, but then empowered project participants to develop and evolve this drawing on their own interests and heritage.

- *ISCOM* introduced the concept of communal decision making, rather than hierarchical discussions, involving people of all ages and bringing together both women and men.
- *ROOTS* used arts media from the Caribbean, Africa and the UK to help the project team explore their identity.
- *Tassibee* drew on western styles of group work and education, alongside drama, art and crafts, to encourage women to support each other and come together as a self-help group.

Using Disability Equality Training to explore issues and identities

The benefits experienced by *ISCOM* and *EQUALITIES* in providing Disability Equality Training suggest this might warrant higher prioritisation as a tool for recognising people's experiences and identities as disabled people alongside cultural heritage.

EQUALITIES and *ISCOM* ran Disability Equality Training sessions for workers and users, led by experienced Disability Equality Trainers. For *ISCOM*, this session was held towards the end of the project and it proved incredibly valuable in stimulating discussions between participants (younger and older people, women and men) about the meaning of impairment and disability within their community.

Using arts media to explore identities and develop skills

Both projects run by *Tassibee* and *ROOTS* used different arts media to explore their cultural heritage to great success. This gave individuals different ways to share their stories. It also enabled the development of hidden creative talents.

Women on the *Tassibee* project took the arts media offered by the co-ordinator and developed them into their own projects: a simple role-playing exercise turned into a play performed at *Tassibee's* Eid party; a session using sewing resulted in a collage depicting a typical rural village scene reminiscent of the women's childhoods.

Using trips and events to build confidence and group bonding

The projects by *Tassibee*, *ROOTS* and *ISCOM* all provided opportunities for participants to go on trips as a group or on behalf of the group. This was important as many participants had been or had become isolated from their local community as well as other aspects of their cultural heritage. This may have contributed to a personal sense of isolation and doubts about self-identity, as well as misconceptions about their abilities. Going out together had the double effect of increasing individual's confidence to go out and the group's visibility in the local and wider community. In some cases, these trips were to regional or national conferences, which also helped widen the project's and organisation's networks and knowledge.

- *ROOOTS*: the project team walked around their local African Caribbean community, using local shops and services. Team members also attended national conferences on behalf of the project.
- *Tassibee*: women from *Tassibee* made trips to London, Leeds and Birmingham, to conferences and to social events.
- *ISCOM*: some of *ISCOM*'s service users went on trips to the seaside, Kew Gardens and a tour of central London's main attractions.

Faith and religion

Faith and religion were especially important in three of the projects, providing inspiration and motivation for working to improve support for disabled people within their respective communities. *Tassibee* is a Muslim organisation. Most of the people using *ISCOM*'s services are also Muslim. *ROOOTS* showed how important the role of churches can be in community life during PATH training sessions. For many workers and participants, their personal faith was important in the way they and others interacted and cared for one another.

Religion can also affect how different communities approach disability. For some religious denominations, different impairments or health conditions may have a stigma attached. Attempting to address this was beyond the scope of these projects. For other people, religion and faith promote positive action to support and assist disabled people.

Language

When a project or organisation is working with a black community, the language used can open access or create a

Emerging lessons from four grass-roots projects

barrier. *Tassibee* took considerable care to use appropriate language both to promote the project and throughout training and self-help sessions.

Tassibee sought to challenge the language inequality by delivering the training in two classes: bilingual (Punjabi and English) and just English. Both classes had co-trainers; one a Pakistani Muslim woman and one white English non-Muslim. It was important for women to see languages as having equal value. The project validated the participants' first language, which gave them confidence in their second. For some women, it enabled them to use their hesitant Punjabi without fear of ridicule; for others, it offered the chance to improve their English.

If all the organisational work is done in English, it puts limits on who can get involved for those who cannot speak and understand English confidently. Similarly, training delivered in English, even with translation, risks reinforcing ideas that white people and English speakers are superior to people who can't speak English or who lack confidence in doing so.

Challenging myths and prejudices

There are myths about the skills and abilities of disabled people. These include: 'black people don't do voluntary work' and 'all Muslim women are downtrodden and powerless'. Organisations working to improve support for black disabled people have a role in challenging such myths within and outside their own communities and organisations, and also on the part of disabled people who may have low expectations of themselves following years of discrimination.

- *ROOOTS* showed that people with learning difficulties can organise training events and conferences, make presentations, create works of art and encourage service providers to think broadly when planning services.
- *Tassibee* challenged prevalent white British assumptions about Muslim women. It is an empowering organisation, enabling women to be educated, assertive, powerful, in control of their lives, healthy and comfortable with their identity.
- *ISCOM* showed that black people do voluntary work, since almost all the workers at *ISCOM* are unpaid volunteers. In fact, the project worker for the JRF project was the organisation's first paid worker.

Shared and separate spaces for disabled people and carers

The mainstream (white-led) disability movement has often focused on separating the politics and needs of disabled people from those of carers. In fact, the term 'carer' remains a contested and uncomfortable term for many disabled people, reflecting a long history of carers speaking and acting *for* disabled people, rather than supporting disabled people to speak and act for themselves.

Across three of these projects, the distinctions between 'disabled person' and 'carer' were blurred. Sometimes, project workers and participants were themselves both disabled or experiencing mental health difficulties, but at the same time providing care and assistance to other family members or friends. In other cases, such as for *EQUALITIES* and the user involvement forum in *ISCOM's* Service Plus project, disabled

Emerging lessons from four grass-roots projects

people and family members were brought together because of their shared (as well as different) experiences of discrimination and unmet needs and/or because there was no history within the community or organisation of pursuing separate agendas.

EQUALITIES felt that, for black people, the distinction between disabled people and carers was not helpful. It did not reflect the more holistic approach to ways of supporting each other within families and communities. In addition, the replies to advertisements for the project solicited a very strong response from local black carers indicating: their interest in attending; their frustration at not having a similar and specific forum for black carers; and their desire to come together with disabled people on the issues. *EQUALITIES* therefore opened up the initial partnership meetings to carers as well as disabled people, and later pushed for change and representation on issues affecting everyone.

For other projects, providing separate spaces just for disabled people to come together to work or support each other was appropriate and vital to create a safe space for those involved without their carers present. Direct training or self-help groups are two examples when it is likely to be beneficial for black disabled people to work without their carers, but with supporters.

ROOTS employed black disabled people as workers and therefore its activities were without carers. This was found particularly helpful, enabling the project team members to exceed their own and others' expectations. It also gave them an accurate experience of paid employment.

Building individual and organisational capacities ...

... Through increasing the number of skilled volunteers and workers

Black community workers have significant skills that are not always fully recognised. In small voluntary sector organisations, one worker often fulfils at least the following roles: community development worker, trainer, support worker, volunteer supporter, recruitment officer, fundraiser, finance officer, outreach worker, project manager, publicity officer and marketing manager. In mainstream organisations with more resources, each of these roles is likely to be performed by a separate worker. In black community organisations, there is usually the added skill of having to fulfil these roles in at least two languages.

The few staff there are can quickly get burdened with heavy workloads and responsibilities. The problem can be self-perpetuating: only one worker has the experience to run a project so only that worker ever does. Training new staff and volunteers takes a good deal of time, resources and energy. Retaining trained staff and volunteers relies heavily on securing long-term funding, otherwise staff and volunteers may move on to other paid work. *Tassibee* explicitly set out to address these difficulties, but was frustrated in this by the short-term nature of the funding provided.

... Through training

Where there were new workers, the projects provided additional training and learning opportunities about race, culture

Emerging lessons from four grass-roots projects

and disability equality. Individual disabled people involved in some of the projects also received training as a core part of the project. This gave them increased confidence about their skills and abilities as well as their rights.

- *ISCOM*: the project worker attended events marking European Year of Disabled People and the organisation also received Disability Equality Training (open to service users as well as project workers and volunteers). This training was delivered by a black disabled person experienced in providing equality training.
- The *ROOTS* team was trained in presentation and organisational skills so that they could train local service providers.
- Women on the *Tassibee* project were trained to facilitate the self-help groups.
- The *ROOTS* team performed a role play that showed a person with learning difficulties being interviewed for a job as a chef. The interviewer tried to persuade the applicant that a person with learning difficulties would be better suited to a lesser skilled role (such as a glass collector), despite the training or skills of the individual being interviewed. At the start of the project, some of the *ROOTS* team members would have accepted the less skilled role; by the time they came to work with other organisations, they were all confident about their rights, skills, ambitions and abilities, and were able to encourage people to stand up for themselves and not accept this kind of behaviour by a potential employer.

... Through networking

Networking is hard work and time-consuming, and can therefore seem like a drain on resources. However, in the long run, it can help to improve the organisation and project through increasing knowledge and raising the project's profile. All four projects intended to do some networking as part of the project, although this proved difficult to sustain across the board.

ROOOTS project team members found that, by attending conferences, individuals built up their knowledge about support for black people with learning difficulties. They also publicised the work of *ROOOTS*, which will help in the future as it works towards becoming a social enterprise. *ROOOTS* also benefited from the support workers and manager being well-known through social or professional networks in the community and around the city.

Formal networks are hard to establish. The project led by *EQUALITIES*, initially to set up a collective partnership of local black disabled people's and carers' organisations, was an ambitious one to attempt in such a short time. Embarking on the project, knowing that the sector was frustrated, poorly resourced and disillusioned, was courageous.

... Through data collection and monitoring

One aspect of organisational capacity and development that all the projects found difficult and time consuming was collecting and monitoring relevant data. Systematic data monitoring is actually more useful to organisations than it is to funders. It can show who the work is benefiting, how they benefit and how they found out about the organisation. It can therefore help to direct

Emerging lessons from four grass-roots projects

future work and provide evidence for funding bids. Without monitoring, it is difficult for organisations to prove a need and that they can meet that need.

ISCOM succeeded in building its organisational capacity to develop a system to record information about cases, advocacy and advice work. This was motivated in part by requirements for registration as a provider of immigration advice.

Paying project participants and volunteers

There are debates about paying participants for their time given to a project. Sometimes this is about paying service users a nominal sum for their expertise when designing and managing services. Sometimes this is about employing service users to run projects. Within some of the projects, the level and type of payment needed to be carefully discussed. A balance was sought between using money to recognise the work people had done to contribute to the project, yet not saying ‘this is how much we think you are worth’ or ‘we don’t value people who do not want to be paid for whatever reason’.

- *ROOOTS*: members of the project team were paid the maximum that would not have affected their other benefits; the project work was arranged around this. This meant that the team members and support workers looked positively on the project as employment.
- *Tassibee* found that, for some women who were facilitators (paid a sessional rate), the money they earned helped build their self-esteem and respect in the

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community. For some, it was the first time they had their own income. It gave them the confidence to start looking for other work. This can be a way to move people on quicker than through unpaid, voluntary work.

- *ISCOM* gave payment in kind to the members of the forum by running activities and events, and providing good food.

Although the JRF funding covered payment for participants, volunteers and project workers, it is important to acknowledge that all four organisations relied on the use of volunteers in the rest of their work. This challenges the myth that black people don't do voluntary work.

One project commented on the difficult balancing act, especially for a small community organisation that is already overstretched, of supporting staff who have mental health difficulties. The organisation needs and wants to support the worker, who may need time off because of their mental health. However, the organisation also needs to keep running.

Meeting people's basic needs

Sometimes it was more important to meet the basic needs of black disabled people, particularly if they had recently arrived in the UK, than to work on other aspects of the project that had been planned.

The project worker at *ISCOM* found that sorting out housing and benefit problems for Somali disabled people was more important than developing the user involvement forum. It was easier to develop this at a later stage in the project, when people's basic and immediate needs had been met.

Working under difficult circumstances

Sometimes, projects have to deal with local circumstances and political developments that are beyond their control.

EQUALITIES particularly suffered a setback with the local authority being placed on Special Measures.

EQUALITIES wanted to establish a collective partnership of black disabled people and carers in the area. However, local groups supporting black disabled people and carers did not have the resources to send representatives to meetings. Instead it was overwhelmingly black disabled people and carers who attended the forum meetings, having heard about them through word of mouth. Without more resources for local community groups, and a commitment to the work, the partnership was not sustainable.

EQUALITIES then used direct lobbying, which initially proved more successful even though this was a less collective approach. Ultimately, however, this also hit barriers.

Sometimes, it is wider developments that put projects under additional pressure to do, and be seen to do, well. For example, at a time when Islamophobia is increasing and Muslim communities are often portrayed in a negative light, even as enemies of the UK, organisations like *Tassibee* and *ISCOM* are trying to work in a positive, productive and peaceful way so that their members and participants are part of British society while not losing their cultural and religious identity.

Supportive allies

Projects and organisations aiming to improve support for black disabled people benefit from having strong powerful allies. These can bring relevant and helpful skills or contacts that might not otherwise have been available to the core project team, such as research skills and knowledge of new developments and techniques, funding application support and strong personal and professional networks.

One project benefited from having a high-profile black disabled woman leading the project, but it did not have a consistent powerful ally in the local authority with which it was trying to work. The BME Alliance (bringing together the black voluntary sector in the borough) was very supportive of the project, but it too lacked resources and sufficient recognition from the local authority. This project found it harder to reach its original goals than the other projects. The other three projects benefited from support from white people. This does not mean that, in order for a project to succeed, it needs a white ally who is powerful. But it does raise some important and uncomfortable possibilities that warrant further investigation.

First, what are the implications of there being more white people in powerful positions where they can be allies for community interests and organisations? Second, are white people in positions of power more likely to listen to a white person advocating for black people than to black people directly; and, if so, what does this say about how skilled black community workers are recognised and valued? Third, what is the importance of having an ally who can speak English if this is not the first language of the community organisation?

Funding

All four projects were run by voluntary sector organisations. This means that they faced the same funding challenges as other organisations in the sector. It is a complex area to examine, but it was suggested that those organisations that provide support to black disabled people experience these problems more acutely than others where people's identities, support needs and experiences of discrimination can be particularly complex.

The projects were keen to stress that it is not necessarily about the amount of funding that is available, but the way it is distributed:

Is it able to be reflected in the report – it isn't just about 'we need more money'. There is a problem in the system where projects are not able to be honest about the project to funders.

(A worker on the *Tassibee* project)

Two particular problems highlighted by these projects are reliance on short-term funding and lack of flexibility. With a focus on project funds, and an inflexible funding scheme, organisations are more likely to feel that they cannot be honest with their funders about challenges and changes.

Short-term funding

Development work is a slow process and it is difficult to achieve far-reaching changes in a short timescale. Yet funds are increasingly distributed on a short-term basis. These can be helpful to allow organisations to try something new but, all too often, community organisations end up depending on short-term project funding for survival and to meet core community

needs. This means that: managers spend much time chasing funds rather than supporting workers; organisations bend their needs to fit the criteria of project funding; long-term planning is not possible and short-term goals take priority over community development. Core funding is often explicitly excluded from project funds which prompts the question – where can community organisation get core funding from?

Flexibility

Flexibility is crucial. Project managers and workers need to be flexible and open to changing plans to respond to service users'/participants' interests and wishes, as well as to external developments in the local or wider community. In turn, this means that flexibility is important on the part of the funding body, to enable projects to evolve appropriately and to take forward work that they know is a priority for the beneficiaries of the project.

All four projects welcomed the funding flexibility provided through the *Making Change Happen* programme. This reflected an acceptance of the developmental and even experimental nature of the projects, and also a commitment to promote the active involvement of service users in shaping and delivering the projects – thereby necessitating flexibility around process and outcomes.

ISCOM was clear it needed an advocacy worker to meet the needs of its disabled members. It was also keen to start to develop user involvement. It combined these two needs into its proposal to the Foundation. The user involvement aspect was part of the funding criteria; the advocacy worker was not, but the funder accepted this as an important part of

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making user involvement possible. However, in the end, although a user forum was set up, it was indeed the advocacy side of the work that proved more successful in making change happen.

Summary

This chapter raises a variety of issues that the groups faced. As previously acknowledged, all four grass-roots development projects were the product of voluntary sector organisations. It is worth noting that many of the dynamics described above are familiar to organisations in this sector, particularly those from minority ethnic communities. It is important to recognise that projects supporting black disabled people experience these issues in addition to any problems arising from the complexity of discrimination felt by their service users. Often, these pressures, particularly financial constraints, are more challenging than pressures specific to the support work itself.

4 Case study 1 ROOOTS: black people with learning difficulties training service providers

Introduction

ROOOTS is a team of African Caribbean people with learning difficulties that trains organisations to provide services that are accessible to, and appropriate for, African Caribbean people with learning difficulties. It uses a mixture of role play and other forms of presentation to highlight the issues involved, and a planning tool called a PATH explicitly to plan change. *ROOOTS* is managed and supported by experienced staff from *People in Action*.

People in Action is a large multicultural organisation. It empowers people with learning difficulties to take an active role in life, largely through leisure activities. It is based in Leeds and employs six full-time equivalent, 20 sessional staff and many volunteers. *People in Action* is part of a wider network of local organisations for and of people with learning difficulties, such as Connect in the North (which provides training for organisations working with people with learning difficulties) and the local Learning Disabilities Partnership Board. It works with all people with learning difficulties, with some specific groups: young people, women, Asian people and African Caribbean people.

DRIVE is the steering group for the organisation's work with African Caribbean people with learning difficulties. It comprises mainly African Caribbean people with learning difficulties and is supported by *People in Action*. As part of its planning process, in 2002, DRIVE identified that service providers did not appear

to take the specific needs of African Caribbean people into account when planning and delivering services for people with learning difficulties. DRIVE wanted African Caribbean people with learning difficulties to show service providers why things needed to change and what could be done. DRIVE also wanted people with learning difficulties to be paid for their work as financial recognition of a socially valued role. These strands formed the basis of *People in Action's* plan for *ROOTS* and proposal to the Joseph Rowntree Foundation's *Making Change Happen* programme.

Aims

- To use direct experience, shared learning and good-practice examples to promote positive change in the attitudes of staff working for local service providers and the culture of other organisations, including the Leeds Learning Disability Partnership Board and associated groups.
- To support service providers to develop accessible and appropriate services for African Caribbean people with learning difficulties.

Timetable

The first few months were taken up with recruiting the project team (six African Caribbean people with learning difficulties) and the arts development worker.

In addition, a survey to all relevant service providers identified a number of organisations keen or willing to work with *ROOTS*. This survey also established a baseline of existing practice from which to work.

Improving support for black disabled people

For eight months, the project focused on training the project team. They met weekly at a venue in Chapeltown, an area of Leeds with a large African Caribbean population. They used different arts media to explore the history of African Caribbean people, and spent considerable time getting to know and be part of the local community.

All team members participated in at least one local, regional or national event on behalf of *ROOTS* (such as the national People First conference in Manchester and a research dissemination event in Birmingham).

A 'taster day' was held to show potential participating organisations what might be involved if they booked training from and agreed to work with the *ROOTS* team as part of the JRF project. Seven organisations signed up. Training was tailored to suit the organisations, although the basic plan was one day of presentations from the *ROOTS* team members and one day (led by *People in Action* staff) to create a PATH for the participating organisation.

Towards the end of the project, *ROOTS* organised, hosted and chaired a conference to share their experiences more widely and generate publicity. A video, which included much of the conference, was also made about the project. Additional funding was provided for an exit strategy, which was used to determine the future direction of *ROOTS*.

Process

Six African Caribbean people with learning difficulties were recruited (through a formal process of application, interview and selection) to form the core project team, supported by experienced support workers and an arts development worker (employed by *People in Action* to work on this project).

The original plan focused on Forum Theatre as a means of change. This is a training tool used internationally by oppressed people overcoming injustice (Cardboard Citizens, 2004). However, the arts development worker broadened the project to provide team members with the opportunity to explore their identity through music, poetry, collage, writing, drawing, dance, film and batik.

All *ROOTS* team members were also involved with other activities within *People in Action*, such as being part of the local carnival and attending events as part of Black History Month. It also included enabling the project team to get to know Chapeltown better. The team used local services, met at local venues and used the local internet cafe.

It cannot be overstated how important this stage of the training was for the *ROOTS* team. In order to help other service providers and organisations recognise and challenge discrimination, the team first needed to feel secure about its own identity, experience and understanding of these issues. Exploring their history, culture and experiences of discrimination enabled the *ROOTS* team members to do this.

ROOTS asked that the same people attended both training sessions in order that the presentations had most impact on the planning. They also requested that people with overall management and responsibility participated (not only frontline staff), in order that action planning could be done with knowledge of budgetary and other constraints.

ROOTS used an inclusive planning tool called a 'PATH', which is often used in 'person-centred planning' with individual people with learning difficulties and other service users. The important thing to note about a PATH is that it is a very creative process. It is highly visual, and encourages all involved to think

Improving support for black disabled people _____

broadly and imaginatively about what is possible. It then moves from broad visions to more focused plans and specific commitments to tasks and deadlines.

The project team members gradually took on more responsibility for hospitality and arrangements as the project progressed. One of the project team members chaired the conference at the end of the project.

What are the training sessions for service providers and organisations like?

A session with the *ROOTS* team is fun and interesting as well as informative and educational. You are welcomed with Caribbean music, introduced to the various team members and offered refreshments. Examples of the work of the team are around for you to look at while you await the formal start. Sitting in a circle, rather than lecture style, everyone present will introduce themselves, using a warm-up exercise rather than simply stating your name. This is often amusing and helps you to feel that you are in a safe, comfortable and relaxed atmosphere. Members of the team then give a number of presentations, perhaps talking about some of their life experiences, or acting out a role play, or sharing their feelings through movement and narration. All of this is presented in a way that leaves you feeling able to ask questions without fear.

Lunch is provided by a local Caribbean catering company. Over lunch, you have plenty of opportunity to chat with the team members, either about their experiences of discrimination or sharing your tastes in TV and music, and what you like to do at the weekends. After lunch, there is time for another presentation and an introduction to the PATH planning tool.

Your second day is much harder work, though still in that relaxed, comfortable *ROOTS* fashion. Again welcomed with music and a drink, you will be led to the PATH planning area, where the PATH is on the wall, waiting for your contributions. A facilitator guides you through all the stages, but you will be expected to do the work. It is *your* organisation's plan for you to take away and use.

Outcomes

The skills of the individual members of the *ROOTS* team were significantly developed. They kept a record of their work in a personal 'learning log', which they completed each week. This showed a clear progression in knowledge, confidence, awareness and practical skills as the project grew. Team members have also developed a range of artistic, creative and presentation skills, and a clearer understanding of discrimination and human rights.

Importantly, the individuals who came together to form *ROOTS* have developed close working relationships as well as friendships with each other within a short period of time (they did not all know each other before the project started). This has been facilitated by the skills of the support workers and by the use of life stories and creative media, and by allowing enough time in the early months of the project for the team to develop and to steer the project themselves.

During the JRF-funded project, seven organisations participated in some form of training with the *ROOTS* team, with excellent feedback and good progress reports several months later. The PATH as a planning tool for organisations, as well as for individuals (as was originally intended), proved to be

Improving support for black disabled people

very useful. The *ROOTS* team used it to good effect in its work with local organisations and service providers. There have been concrete actions as well as good planning.

The Leeds Family Placement Service, which provides short breaks for disabled people, participated in the training. The presentations helped to generate ideas in order to put in place a strategy to increase the number of African Caribbean carers through a combination of community involvement, advertising and local information meetings. It has begun working with local organisations to recruit new carers.

The Leeds Home Farm Trust branch used its training sessions with *ROOTS* to help it focus on gaps in its services. As a result, it has been able to improve its care to ensure that physical and cultural needs of African Caribbean residents are met and not overlooked.

Because of the project, the team has also changed its own and other people's perceptions of the capabilities of people with learning difficulties. This emerged clearly at and following the conference. Delegates admitted to being far more impressed than they had expected by the quality of the conference and the presentations by the team.

A further sign of external recognition of the team's achievements was the Mary Seacole Black Achievers Award (in both 2003 and 2004), presented to the *ROOTS* team at a high-profile event at Leeds Civic Hall hosted by the Mayor.

Learning from this project

The main support workers had worked well together for *People in Action* for a number of years and were highly respected by other organisations in a number of networks. The arts development worker had previously been a volunteer with *People in Action*. This meant that all six people with learning difficulties in *ROOTS* had already met the staff team before the project. The good staff team was one of the reasons for the success of the project.

Considerable time was spent exploring cultural heritage, expressing experiences of discrimination in drama and art forms, and practising making presentations. It is important to recognise that doing this correctly takes time – more than originally allocated. The project team would have benefited from even more time. It was agreed to set aside one aspect of the original proposal (setting up action learning sets with local service providers) and to delay delivering training to other organisations until the *ROOTS* team members were confident about their own knowledge and skills. It would therefore have been better had this been a longer project, allowing the whole of the first year for building up the skills and expertise of the team.

It is important to balance the informality of the training sessions (which was much appreciated by participants) with good timekeeping skills.

Organisations that participated in training sessions have since recommended *ROOTS* to others. This suggests that the approach and methods used by the project, particularly the central role of people with learning difficulties and the use of arts, presentations and the PATH planning tool, can be an effective model for change.

The exit strategy was useful in order to prioritise areas of training and to clarify sustainable funding opportunities.

5 Case study 2 *Helping Each Other, Helping Ourselves*: self-help groups supporting Pakistani Muslim women

Introduction

Helping Each Other, Helping Ourselves was a series of self-help groups supporting women with long-term mental health difficulties. The facilitators were trained and supported as part of the project, using life-story approaches, group-facilitation techniques and a variety of arts media. The project was run by *Tassibee*.

Tassibee is a Muslim organisation supporting women's development in Rotherham. It started as a prayer meeting, and has developed since into a large developmental training provider. It remains firmly grounded as a Muslim organisation. It works very well in partnership with non-Muslim groups and individuals, and receives support from the local Community Mental Health Trust.

It is a place where Muslim women find safety and comfort in a sometimes very troubled world. They are able to practise their faith with other women, learn more about Islam, while at the same time learning English and gaining new practical skills such as computing. It is a very flexible organisation, trying to meet individuals' needs, rather than trying to get individuals to need what it can provide.

Many women come through its open doors, learn new skills, gain confidence and then move on to other education courses

——— *Case study 2 Helping Each Other, Helping Ourselves*

or employment elsewhere. This is a tribute to the hard work put in by the organisation's co-ordinator and the sessional and part-time workers. However, it means that *Tassibee* is always looking for new staff, as volunteers or paid workers.

Previous research (Smith, 2001) identified the need for support for young mothers and older women in particular, and recommended the use of life-story approaches.

Aims

- To offer support in the form of self-help groups to women with long-term mental health difficulties.
- To build capacity in the organisation and thus reduce pressure on *Tassibee's* co-ordinator.

Timetable

At the start, a steering group was established, comprising *Tassibee's* co-ordinator, a white researcher and long-standing ally with *Tassibee*, a young mother, an older woman and a representative from the local Community Mental Health Trust. The project worker appointed to co-ordinate the self-help groups and facilitators also joined the steering group. This group met regularly throughout the project.

Training sessions ran once a week for ten weeks. The first week was a taster session so that potential participants had a chance to find out what was involved. The training course was held bilingually in Punjabi and English in the morning, and just English in the afternoon. The two groups had lunch together. The training course introduced the women to facilitation

techniques and practical tips on running groups. A feedback session was held at the end of the training.

All women who had attended the course were invited to apply to be support workers to facilitate the self-help groups. Five were appointed.

The self-help groups met throughout the autumn and winter 2003–04.

Process

It was difficult to ‘sell’ the training course for two particular reasons. First was the training approach. Most of the participants were used to a passive ‘chalk and talk’ type of education, and found it daunting being expected to direct the learning and to contribute actively. It was hard at first for them to see this as empowering rather than as *Tassibee* negating its responsibilities, but gradually they came to terms with this.

Second, the benefits of talking and sharing personal life stories were not immediately clear to the women. It can seem self-indulgent or boring to talk about life experiences. However, using a ‘memory bag’ during sessions proved a very useful tool in working with life-story approaches. This enabled women to pull out old memories they might have forgotten and remind themselves of their value. It also enabled them to put away memories that they didn’t need and didn’t want to keep. This dual purpose was valued by all who used it in the training course and later in the self-help groups. It unlocked memories in a relaxed, informal setting, sometimes with tears, sometimes with laughter.

———— *Case study 2 Helping Each Other, Helping Ourselves*

Sharing life experiences can be daunting within a small community, where it can seem as if everyone knows everyone else. Ground rules of trust and respect were crucial in giving women a safe space to talk about difficulties and problems.

The feedback after the training course showed that it was very valuable, even to those women who didn't go on to become support workers. In itself, it was a supportive group. The dual-language approach was much appreciated by the participants, but put considerable strain on the trainers. At the feedback session, not all the women felt that they could go on to become support workers because they still lacked confidence. In some cases this was overcome.

Support workers were employed for four hours per week – the two-hour self-help group sessions with preparation time. The project co-ordinator was employed for 18 hours per week. She was involved in the recruitment and supervision of support workers, as well as working on publicity and raising awareness.

A crèche was provided during both the training and the self-help groups so that childcare needs would not prevent anyone attending. This was free to participants, included in the budget of the project proposal.

Some of the women in the self-help groups found it very hard to describe the group and its benefits to their families. Just as it had been hard to 'sell' the training course to the women in the first place, it became hard to 'sell' the group to other people. This problem is not peculiar to the Pakistani Muslim community; others setting up self-help groups in and for other communities have faced the same difficulty. There may have been the additional problem that mental health difficulties are not discussed freely within the community, but there was no specific evidence for this.

Improving support for black disabled people

In the end, it was found that just talking within the groups was not enough. Different activities (including those that did not originate within the women's own culture) were introduced, which made the participants feel relaxed and comfortable. These included sewing, drama, aromatherapy and crafts. Sometimes, after introducing an activity, the women developed it. A sewing session turned into the creation of a collage picturing rural Pakistani village life. A session involving role play developed into a play about village life, marriage and Eid, which was performed at *Tassibee's* Eid party in 2003. This was an example of the women taking an idea offered to them and expanding it.

The support workers met regularly throughout the project. This had not been planned in the initial proposal but problems arose with communication and misunderstandings. If the support workers had met regularly from the start, some of the problems might have been avoided. When they eventually did start to meet, they went through the job description with the project managers and discussed what was expected of them. The support workers also produced a list of responsibilities and tasks. This negotiation and clarification helped everyone involved.

Outcomes

For the organisation

Although the capacity of *Tassibee* was not increased (as initially hoped), the project served to highlight areas of need for the organisation. It enabled the co-ordinator to prioritise securing long-term funding for *Tassibee*, and to highlight their strengths

——— **Case study 2 Helping Each Other, Helping Ourselves**

as a training and employment support organisation in the hope that this might attract funding from new sources. In some senses, the JRF-funded project exacerbated the capacity problem; women were increasingly assertive and confident about their needs, and became able to demand more of the co-ordinator's already stretched time and energy. This is not an uncommon problem in a voluntary sector organisation dependent on short-term project funding.

One unexpected outcome of the training period was an increased sense of equality between the younger and older generations of women taking part. They realised that they had had similar experiences, but had dealt with them differently. They felt able to learn from each other, with everyone having something to offer. One of the younger women indicated that it had been the first time she'd spent time in the same room as all the 'aunties' (a respectful yet familiar term used to describe older women in society, not necessarily any blood relation).

For individuals

I've not seen a course like it. Sometimes you go home from a course more depressed than when you arrived, but not this one. It was relaxing and confidence building. It was therapeutic for those with problems or mental health illness. The group was harmonious, there were lots of giggles and it was really enjoyable. *[The trainers]* took things women never thought they had out of them. It was the best course I've ever been to. It doesn't make you strung up. You could get out what you have but don't realise it. *[The trainers]* opened the door through their good explanations. (Woman attending the facilitators' training course)

Improving support for black disabled people

- All five of the support workers progressed to something else (employment or education) after working on the JRF-funded project, as a result of their increased confidence.
- One of the support workers (who had previously been very isolated and unconfident) was appointed to the *Tassibee* steering committee. She could also be found conducting informal outreach on behalf of *Tassibee* in Rotherham.
- One of the younger women had initially disliked the training sessions because she was expected to speak and contribute. In the past she hasn't wanted to take risks, and lives with her mother and her young daughter. Since the JRF project, she has applied for a job. This represents a genuine increase in confidence for this young woman.
- Another young mother, who had been severely depressed for a number of years, was offered a job at the end of the JRF project. This project gave her increased confidence and experience of working with other people within a safe environment.
- One older woman was conscious of her loss of status when she moved to England from Pakistan. In Pakistan she had had a good job and earned her own income. Since coming to England to live with her son and daughter-in-law she has had no money and has felt the loss of status. This project enabled her to earn some money and rebuild some self-respect. She went on to do another course.
- A number of the women, both older and younger, went on to attend a childcare course, which could eventually lead to them being qualified childcare workers.

———— *Case study 2 Helping Each Other, Helping Ourselves*

- One of the women who starred in the play at Eid admitted that she had always wanted to do some form of drama but had never felt able to say. Being in the self-help group had helped her to fulfil this wish.
- At the feedback of the training course session, it was noticeable that the group of women boosted and supported each other. They were good at listening to each other, even when they all had a great deal to say and when some of this was fairly critical of different generations. All the women (not just the trainers) sought out the thoughts of quieter members of the group and all were good at complimenting each other on use of language, written or spoken. There were also incidences of women clearly expressing their needs and others offering their services. One woman said she'd like to learn Urdu and another immediately offered to teach her.

Learning from this project

This project offers a good model of change based on training local women (current or potential service users) to be facilitators, and to use these skills in facilitating self-help and peer-support groups.

The 'taster session' before the course was a good way to allow women to explore the possibility before committing themselves to the full course. This helped to ensure that more women who started the course completed it, since they had more idea of what the course would involve.

It was difficult to 'sell' both the training course and then the self-help groups. Careful explanation was needed in order that the project would appeal to the people who could benefit the most.

Improving support for black disabled people

Recruitment to the self-help groups took longer than expected. It was time consuming because the project manager was committed to reaching women who would benefit the most from the self-help groups and who were therefore likely to be hard to identify and reach.

The project team recognised that it can be boring to just talk every week. Adding activities helped not only to break down barriers but also to introduce the women to new skills and hobbies that they could take further, as well as skills and crafts drawn from their own cultural and personal background.

The approach of the trainers and facilitators was especially important in achieving success. Participants appreciated the training being conducted in two languages. While the trainers found this more stressful to deliver, it nevertheless allowed participants the freedom to share sometimes difficult experiences in their own language as well as giving ample opportunity to use their second language (in some cases English, in others Punjabi) without fear of ridicule.

The facilitators introduced new ideas and encouraged participation rather than telling the group what to do. At first, some of the women participating in training and groups felt this was an abdication of responsibility. It took time for the group members to feel that this approach was empowering, and allowed them to make decisions about what they talked about and what activities they did.

6 Summary and pointers for practical action

This chapter gives a brief overview of the four organisations and projects examined for this report. It then suggests practical pointers and questions for voluntary and community organisations led by or supporting black disabled people, and questions for funders (statutory, independent, charitable) and service providers.

The four community organisations involved in this programme were very different. *ISCOM* worked with Somali people, many of whom were refugees or asylum seekers. The Service Plus project provided direct advocacy to secure welfare and social care entitlements, and laid the foundations for a user involvement forum. *Tassibee* worked with Pakistani Muslim women in Rotherham. The project provided training and supported self-help groups to improve mental well-being. *ROOTS* was a team of African Caribbean people with learning difficulties, employed and supported by *People in Action* (Leeds). The team was trained to deliver training to local service providers to help them address both disability and racial discrimination. *EQUALITIES* used the funding it received to gather the views of black disabled people and carers in a London borough, and to push for increased recognition of these issues, and a specific space to address them, through local government structures (especially the Community Empowerment Network and Local Strategic Partnership).

The development projects met with varied success. *ROOTS* created a successful model for training and has since secured funding to enable it to develop as a Social Enterprise providing consultancy and training to service providers. *Tassibee*

successfully improved the lives, well-being and confidence of the women who took part in the different aspects of the project, though has suffered from an increase in demands for its services without receiving an increase in resources. In addition, many women on the project have been empowered to take up employment and educational opportunities elsewhere, rather than improve the capacity of *Tassibee*. *ISCOM* made important steps forward in bringing together disabled people and carers. Specific opportunities to discuss issues that affected them were provided, however individual advocacy work took priority.

EQUALITIES experienced the most difficulty in meeting its objectives, in part because of the political and financial circumstances of organisations it hoped to work with, along with the ambitious nature of the project.

From four such different projects, several common themes have emerged. Some are specific to work with black disabled people and their families; others are common across the black voluntary sector, disability organisations and community-based work more generally. Five themes emerged that resonated particularly strongly with the four development projects when they came together to listen to the initial findings of the *Learning the Lessons* project.

- *Identities and life stories*: all four projects invested time in creating safe spaces for people to explore their own identities, share experiences and unravel the impact and implications of discrimination and prejudice in their lives. Sharing life stories and providing safe spaces for people to come together to give each other peer support may sound like 'soft' approaches to improving the life chances of disadvantaged and isolated people. However, in all cases, this model proved powerful and effective in bringing about real changes for the individuals themselves (building self-

Summary and pointers for practical action

confidence and increasing awareness of their rights). In some cases, it also proved powerful when shared with others outside the group, to challenge myths and to push for better services.

- *Drawing from different cultures:* three of the projects successfully drew together techniques, histories and experiences from different cultures. These were fused with strong traditions of faith and heritage, and developed according to the wishes and interests of those involved.
- *Use of different arts media:* one of the most powerful dimensions to the work of three of the projects was the use of different arts media in developing the skills, knowledge and awareness of both individuals and organisations. Drama, music, dance, batik, drawing, writing and story telling were all used to great effect.
- *Funding to make change happen:* all four projects operated on short-term funding contracts (12 months plus an extra £5,000 for each project's exit and sustainability strategy). Short-term projects can certainly change the lives of individuals or a small group of people as several of these projects have demonstrated. However, to improve support to more black disabled people, a longer-term strategy is needed. Changing both attitudes and the way mainstream service providers work will inevitably affect a larger number of people but it will take longer. Projects and funders both need to recognise that such work must have space and resources to evolve and respond to unknowns that cannot easily be explicitly anticipated in the original project proposal. Although the projects welcomed the relative flexibility of JRF, and enjoyed a good working relationship with both the researcher in *Learning the Lessons* and the funder, the

Improving support for black disabled people _____

frustrations and additional burdens placed on the projects by short-term funding were all too apparent.

Some practical pointers for any organisation working to improve support for black disabled people

- 1 Play to the strengths of the organisation. Develop a project that will challenge the organisation, but build on existing strengths and be part of its existing mission.
- 2 Ensure organisational structures and procedures are clear, so that participants and workers can familiarise themselves with the way the organisation works. They need to be robust, but flexible enough to respond to changing needs.
- 3 Work with and learn from other organisations. Sometimes this could mean passing work on to someone more capable, sometimes it could mean joint working. It could mean taking time to attend meetings (local, regional, national) with networking opportunities, so that the organisation stays on top of current thinking, debates, policies and guidelines.
- 4 Seek funds that appropriately address the need of the community or organisation. Ideally, the need should be identified first, through research or the collection of monitoring data, or other specific plan or work. This need should then be explored by the organisation and appropriate funding sought. Short-term project funding is not appropriate for core funding.

Summary and pointers for practical action

- 5 Recognise the importance and complexity of identity: all people straddle simplistic classifications of ethnicity, heritage, disability, mental health, gender, faith, age, generation, class, family and citizenship status. Projects and workers seeking to support black disabled people need to be open to this complexity (additional training for workers may be necessary), and able to provide safe spaces for project participants (clients, beneficiaries) to explore their identities and personal histories.
- 6 Acknowledge multiple oppression. This does not mean that a black disabled person experiences twice as much oppression as a white disabled person, but that both disability equality and race equality need to be addressed alongside other dimensions of inequality and discrimination.
- 7 Challenge your own and other people's assumptions about the needs, abilities and capabilities of black disabled people (including myths and assumptions by funders, service providers, communities, families and disabled people themselves).
- 8 Be prepared for changes and development. Project participants may seize unexpectedly on one particular aspect of a project. This may depend on the flexibility of the funder, and ultimately on the relationship between the organisation, the project's 'service users' or 'beneficiaries' and the funder.
- 9 Different tasks involved in project management and community work need particular skills; not everyone can do or know everything. Seeking additional training and involving others with relevant skills and experience may be essential – for example, Disability Equality Training, or employing an experienced researcher to conduct a baseline audit.

Improving support for black disabled people _____

- 10 Explore ways to ‘fuse’ different traditions and techniques (drawing on long-standing cultural traditions as well as newer media and approaches such as forum theatre, role play and video).
- 11 Explore ways to make the most of available opportunities for influence and change (Local Strategic Partnerships, Learning Disability Partnership Boards, etc.).
- 12 Be realistic with yourselves, your beneficiaries and your funders about what can be achieved.

Questions for organisations, funders and service providers

This section draws on the lessons learned from the four community projects to suggest some questions for consideration by voluntary/community organisations (see Table 1), mainstream services (see Table 2) and funders – statutory, independent or charitable (see Table 3).

Table 1 Considerations for voluntary/community organisations working (or interested in working) with black disabled people

Issue	Yes/no
<i>Identifying need</i>	
Have you identified a gap in service provision?	
Is your organisation the right one to fill this gap?	
Have you the current capacity to do the work?	
Could the work be better done by someone else?	
Are you prepared to hand work over to someone else?	
Can the work be demonstrated or tried out in a short-term project?	
Do you have a realistic, achievable plan for a short-term project?	
Do you have an exit strategy?	
Will you know when the project is over?	
<i>Funding issues</i>	
Are you looking for core funding?	
Is a short-term project appropriate?	
Do you know the differences between different types of funding?	
Are your aims and objectives compatible with the funding criteria?	
Is your proposal clear and carefully costed?	
If you are asking for flexibility in funding, are you clear why?	

Improving support for black disabled people

Table 1 Considerations for voluntary/community organisations working (or interested in working) with black disabled people – *continued*

Issue	Yes/no
Will your project money be clearly assigned in your finances?	
If funded, are you clear about your responsibilities to the contractual funding agreement and what flexibility there might be to revise aspects of the project if necessary?	
<i>Organisational issues</i>	
Does your project allow enough time to identify participants, who may not identify themselves as black or disabled?	
Have you allowed for a varied number of participants?	
Is training needed as part of the project?	
Will the training meet the needs of the individuals?	
Are the premises where the work is to be done accessible?	
Does the project involve service users?	
Does the project give service users opportunities for work experience or employment?	
What language is the project using?	
Is there adequate and budgeted provision for translation and interpreting?	
Do you have a system for monitoring the work?	
Have you planned the end of the project?	

Table 1 Considerations for voluntary/community organisations working (or interested in working) with black disabled people – *continued*

Issue	Yes/no
Do you know who is working on the project?	
Is the level of payment appropriate to the work?	
<i>Content issues</i>	
Have you included Disability Equality Training at the start of the work?	
Have you planned a research or survey element at the start?	
If so, is the research adequately resourced?	
Have you allowed for the fact that people's needs can't be easily categorised?	
Have you planned a 'taster' session at the start for potential participants?	
Have you found sensitive ways to introduce new ideas or concepts?	
Are you trying to meld different cultures in the methods and work that you do?	
Have you given full consideration to the use of 'life stories', 'memory bags', arts (drama, visual, crafts) and other media (video, camera, computer) as techniques to draw on?	
<i>Working with others</i>	
Have you identified other organisations to learn from?	
Have you identified other organisations to work with?	

Improving support for black disabled people

Table 1 Considerations for voluntary/community organisations working (or interested in working) with black disabled people – *continued*

Issue	Yes/no
Have you tried to find out if anyone else has done similar work?	
Have you made contact with people who have already done similar work?	
Have you allowed for participants having needs that are different from those of the project?	
Have you allowed for the fact that other organisations you might work with may view the situation in a different way?	
Have you allowed and costed for a variety of support needs?	
Are you using imaginative ways to express life experiences (e.g. music, art, drama)?	
If you are a large organisation, how are you feeding information to smaller organisations to keep them aware of changes and developments in this area of work?	
If you are a small organisation, have you planned ways to make the most of networking opportunities you do have?	
Are you linking the needs of disabled people with the needs of carers and family members where this is appropriate?	
If your work involves both disabled people and carers, do you allow separate time and space for both groups?	

Summary and pointers for practical action

Table 2 Considerations for mainstream services

Issue	Yes/no
Is the work to support black disabled people sufficiently resourced to meet the needs of the many different communities there might be in your area?	
Do you involve black disabled people and, where appropriate, their families and communities in the design of your support services, and if so, how?	
Do your support services address the cultural needs of the different people who will need the service?	
Do you understand the difference between treating all people equally and treating people the same?	
Are you planning to work jointly with a community organisation?	
If so, is it clear how this partnership is going to work?	
Are you initiating a project that cannot be sustained even if successful?	

Improving support for black disabled people

Table 3 Considerations for funders and contractors of voluntary and community organisations providing support to black disabled people

Issue	Yes/no
Do you distribute funds based only on national targets?	
Can you take into account the needs local to a particular area?	
Are you only offering short-term project funds? (If so, this may undermine organisations' abilities to meet longer-term developmental goals.)	
Are there any ways you can offer core funds?	
What degree of flexibility (about timing, resources, objectives and outcomes) do you have?	
In particular, do you allow for flexibility to ensure that the changing needs of service users can be met?	
Is the degree of flexibility transparent to the projects you fund?	
Are you in a position to support community organisations to develop monitoring systems, structures and (where relevant) standards necessary for official recognition (e.g. for immigration advice work)?	
Can you minimise the time between submission of proposals and acceptance?	
Can you offer extra support if you feel that they have not been realistic in their financial estimates?	

Table 3 Considerations for funders and contractors of voluntary and community organisations providing support to black disabled people – *continued*

Issue	Yes/no
Do you sense that distrust has built up between projects and funders because of a pressure to succeed on a short-term basis?	
Does your funding system encourage openness and honesty from the project, or might projects feel that being too honest about difficulties and changes could be a risky strategy?	
Do you trust community organisations to do the best they can with their resources?	
Do you explain clearly the type of funding organisation you are, along with criteria and expectations you may have of project holders?	
Does your funding system foster creativity without insisting on it?	
Do you engage with organisations on the appropriateness and accessibility of your criteria and procedures, especially when trying to support communities you have not traditionally supported?	

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Appendix: Methods

Data gathered from each project was analysed and then tested out in the other projects in order to determine whether the issue was generally important or relevant only to one specialised project. Where guidance and feedback could be usefully given during the course of the project, it was offered.

Each development project employed different approaches, therefore *Learning the Lessons* used different methods as appropriate to each project – for example: observation (participatory and non-participatory); semi-structured interviews; group discussions and reading literature, background papers and notes from related meetings. It was also important to contact different stakeholders for each project to gain a variety of perspectives on processes and outcomes.

Information was fed back to the projects in a ‘networking day’ after the projects had ended. The draft report was also sent to each project for feedback. Comments, suggestions and criticisms were worked into the final publication.

The nature of contact and the quality of data generated was different with each project.

***ROOTS* (challenging double discrimination project)**

- Interviews: manager, support workers, project team, trainees, others with contact of *ROOTS* or *People in Action*.
- Observation: participatory (own sessions, training sessions); non-participatory (training sessions, conference, *ROOTS* own sessions and JRF project advisory group meetings).

- Documentary: newsletters, minutes of meetings, primary data from research, analysis from research, feedback from organisations from taster day, training and conference, publicity.
- Email: much email contact; very easy to ask questions and get answers as well as arrange meetings this way.

EQUALITIES (Waltham Forest Disabled People and Carers Partnership project)

- Notes from meetings attended, including one with independent observer.
- Copies of minutes received from two forum meetings (attendance not facilitated).
- Observation at organisational training day.
- Telephone interviews with possible forum members and other local organisations.
- Attendance at JRF project advisory group meeting.
- Copy of consultancy report to review the organisation's current capacity and develop future vision (funded through additional JRF funds as part of an 'exit strategy').

Tassibee (Helping Each Other, Helping Ourselves project)

- Introductory meeting at start of project.
- Telephone interview at end of training period.

Improving support for black disabled people _____

- Meeting with trainees at end of training period.
- Observation and informal discussion at Eid party.
- Observation and informal discussion at young women's group.
- Some correspondence (electronic and paper).
- Received publicity materials and notes from relevant meetings at *Tassibee*.
- Received own evaluation of training course.
- Attendance at one of three JRF project advisory group meetings.

***ISCOM* (Service Plus user involvement and advocacy project)**

- Introductory meeting at start of project.
- Phone interview with project manager.
- Meeting and interview with project worker.
- Informal interview with service users.
- Observation at Disability Equality Training Day.
- Observation at two forum meetings.
- Attendance at two JRF project advisory groups.