

Making change happen for black and minority ethnic disabled people

Four grassroots development projects were supported by the Joseph Rowntree Foundation to generate practical learning about how to make change happen for black and minority ethnic disabled people. *EQUALITIES* aimed to increase the local voice of black and minority ethnic disabled people and carers. *International Somali Community Trust* employed direct advocacy and set up a user forum for Somali-speaking disabled people. *People in Action* supported *ROOTS*, six African Caribbean people with learning difficulties, to deliver training to local service providers. *Tassibee* trained Pakistani Muslim women with experience of mental health difficulties to run self-help groups. Becca Singh was commissioned to work with these projects to identify common lessons. The study found that:

- Black history and heritage, faith and strong cultural traditions played a key role in three projects, for example in providing the inspiration for and focus of the projects, and in building trust with participants and the wider community.
- Projects were most successful where they responded from the outset to the complexity of participants' identities, multiple support needs and experiences of multiple exclusion.
- Sharing personal life stories in safe group settings (training sessions, user forums, self-help groups) proved highly effective in changing individuals' lives.
- Projects and participants benefited from:
 - handing over decision-making to the participants directly involved;
 - blending new ideas with valued traditions;
 - using different arts media;
 - accessing disability equality training;
 - getting out and being part of the local community;
 - local and national networking.
- Flexible funding arrangements supported experimentation, enabling projects to change pace and process. However, having short-term funding put organisations under strain.



Background

The Joseph Rowntree Foundation (JRF) has supported a programme of research on the views of disabled people from black and minority ethnic communities and their experiences of service provision (see 'Experiencing ethnicity: discrimination and service provision', JRF *Foundations*, September 2004, Ref: 914, for a round-up of much of this work). The research indicated high levels of unmet need, inappropriate and inadequate support services, and experience of discrimination in mainstream service provision and sometimes within people's own communities. To generate practical learning on making change happen for black and minority ethnic disabled people, the Foundation supported four grassroots development projects and commissioned a researcher to work alongside them.

Lessons emerging from the projects

Although the projects were different in aims, approach, organisational history and capacity, and in the communities they served, several common lessons emerged over the twelve-month funding period.

Project: ISCOM

ISCOM (International Somali Community Trust) in the London Borough of Hackney provides homecare, advocacy, informal home-sitting for carers, befriending, interpreting and translating services for the local Somali-speaking population. Many are recently arrived refugees.

ISCOM's JRF project aimed to empower disabled people and carers both individually through direct advocacy and collectively through a 'user involvement forum'. The project worker – *ISCOM's* first full-time paid worker – visited individual service users regularly and developed systems to record and monitor needs. As a result, the project worker brought to forum meetings issues that came directly from service users. Forum meetings were social events with food, educational speakers and discussions. Towards the end of the project, a disability equality training day was held at one of the forum meetings. This proved popular and useful, and the project might have benefited from holding it earlier.

In terms of outcomes, *ISCOM* has secured funding for two part-time advocacy workers on the back of evidence and data systems developed during the project. Several disabled Somali people have benefited from advocacy work, securing accessible accommodation, registering with a GP and claiming benefit entitlements. *ISCOM* is now more aware of disability equality issues and is seeking funding to sustain the forum.

Project: Tassibee

Tassibee started as a prayer meeting in Rotherham in 1993, and remains firmly grounded as a Muslim organisation. It works well in partnership with non-Muslim organisations and individuals, including the Community Mental Health Trust. *Tassibee* provides a range of training, support and social activities to meet the needs of isolated, multiply excluded women, who are mostly first-generation migrants.

Tassibee's JRF project trained women from the local Pakistani Muslim community, using life-story work as a vehicle for empowerment and change. The women all had direct experience of mental health difficulties. Some who took part in the training went on to develop and support two self-help groups: one for older women and one for younger mothers. The groups used a variety of social and leisure activities alongside life-story work (e.g. using a 'memory bag' to take out and put back both happy and painful memories) to empower women to help themselves and each other.

Many of the women have shown significantly improved self-confidence and assertiveness, and have increased their use of public transport to get out and about. In addition, all five women trained to support the self-help groups have gone on to other courses or paid employment. However, this success has meant that a second aim – to build organisational capacity and reduce pressure on the main co-ordinator – has not been achieved; having trained the women, *Tassibee* lacked the long-term funding to retain them.

Exploring identities and life stories

All four projects invested time in creating safe spaces for people to explore their own identities, share memories and experiences, and examine the effects of discrimination and prejudice in their lives. This may sound like a 'soft' approach to improving the life chances of disadvantaged and isolated people. But it proved highly effective in bringing about real changes for those involved, especially through building self-confidence and increasing awareness of their rights.

The *ROOOTS* group, for example, spent considerable time in exploring identities, heritage and discrimination. This proved instrumental in helping the individual members to come together as a strong team. It also enabled them to use their experiences when training service providers.

Fusing 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.

Project: EQUALITIES

EQUALITIES is based in the London Borough of Waltham Forest, where it provides advocacy services using trained volunteers. *EQUALITIES* promotes the rights of black and minority ethnic disabled people and carers nationally.

The JRF project aimed to set up a partnership of black and minority ethnic disabled people, people with long-term conditions, carers and community groups to influence local policies and services. Local groups lacked the resources to participate in a formal network. So *EQUALITIES* changed course to press for a thematic group on disabled people and carers, with a sub-group for black and minority ethnic disabled people and carers, as part of the Local Strategic Partnership (LSP). After working on this for many months, *EQUALITIES* felt that the LSP was ineffectual and uninterested. *EQUALITIES* withdrew its involvement from the LSP and, later, from the Community Empowerment Network.

The project worked in difficult local and political circumstances, trying to engage a disillusioned and overburdened voluntary sector. *EQUALITIES* tried different ways of influencing strategic bodies, but continued to be frustrated. Since the project ended, a local disabled people's organisation has been commissioned to undertake an access audit in the Borough and develop a disabled people's partnership for the LSP. This is a positive move. *EQUALITIES* is keen to see how far black and minority ethnic disabled people, carers and their organisations will be involved.

In the *Tassibee* project, women in the self-help groups took the arts activities introduced at sessions and developed them into their own projects. For instance, a simple role-playing exercise turned into a public performance for the Eid festival. This drew in a large audience and was greatly enjoyed. The co-ordinators were worried about how the play would be received, but were committed to empowering the women to take the lead.

For *ISCOM*, the strong Somali tradition of passing on wisdom, advice and experience through story-telling, poems and songs shaped the approach to user involvement. The project also combined new ideas of holding open discussions cutting across gender and generation, while using existing separate spaces (such as a women's group) to talk about disability.

Using different arts media

Different arts media were used to powerful effect in developing the skills, knowledge and awareness of individuals and organisations. Variety was important, as different media and activities appealed to different participants. *ROOOTS* initially planned to focus on 'forum theatre', but found it more helpful to use a mixture of theatre, music, drumming, batik, information technology (IT), film and poetry.

Language

Tassibee took considerable care to use appropriate language, both in promoting the project and throughout training and self-help sessions. The project also sought to challenge language inequality by delivering the training in two classes: bilingual (Punjabi and English) and just English. Both classes had co-trainers, one Pakistani Muslim woman and one white English non-Muslim woman. It was important for women to see languages as being of equal value. The project validated participants' first language, which gave them confidence to use their limited second language (for some, Punjabi and English).

Project: People in Action – ROOOTS

People in Action (in Leeds) has six full-time equivalent and 20 sessional staff, and works with people with learning difficulties.

ROOOTS is a group of six African Caribbean people with learning difficulties, who were trained, managed and supported to develop and deliver training to local service providers. The first eight months of the project were spent training the team, using different arts media to share life stories and explore identities and black history. A short survey was sent to local service providers, after which a 'taster day' was held to show what might be involved if they signed up to receive training from *ROOOTS*. Seven organisations signed up. Training was tailored to suit each one, but the basic model was a day of presentations from the *ROOOTS* team followed by a second day (led by *People in Action* staff) to create an action plan for the organisation.

ROOOTS team members developed strong relationships with each other and grew in confidence, practical and creative skills, and awareness of their rights as black disabled people. The training developed and delivered by *ROOOTS* has had a positive impact. For example, one organisation is now working to increase the number of African Caribbean carers providing short breaks in Leeds, using a combination of community involvement, advertising and local information meetings. Since the project's end, *ROOOTS* has secured funding to develop into a social enterprise providing training and consultancy.

Funding change

All four projects had short-term funding contracts (twelve months, £40,000-£50,000 per project). Short-term projects can change the lives of individuals, but changing attitudes and services in ways that affect larger numbers of people takes more time and resources. Such work also needs space to evolve, and several factors – including resistance to change – could not easily be factored into the original project proposals. *EQUALITIES*, for instance, met with more difficulties and resistance than could have been anticipated in the original proposal. Flexible funding enabled the project to try out different ways of achieving its aims. During the project, *EQUALITIES* also broadened its remit to include carers, in response to expressed unmet needs from local people.

The projects welcomed the relative flexibility of the funding, but the frustrations and additional burdens placed on them by short-term funding were all too apparent. Such difficulties are common across the voluntary sector, but may be particularly acute for organisations led by or working with black and minority ethnic disabled people, where people's identities, support needs and experiences of discrimination can be especially complex.

Networking locally and beyond

ROOTS specifically wanted to increase its visibility in the local community by using local facilities (an internet café or caterer) for the project. This helped to challenge local assumptions within the community about people with learning difficulties. Team members also benefited from attending national events and learning from other local groups with shared interests.

All four projects intended to network with others, but two of them found this hard to sustain. For example, the urgent needs of Somali disabled people and carers known to ISCOM's project worker understandably took priority over networking with disability and user-led groups.

For further information

The full report, **Improving support for black disabled people: Lessons from community organisations on making change happen** by Becca Singh, is published by the Joseph Rowntree Foundation (ISBN 1 85935 390 8, price £7.95).

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Conclusion

The study findings gave rise to some suggestions for projects:

- Involve disabled people from the outset and throughout, and be ready to change plans and pace.
- Recognise the importance of multiple identities that straddle 'tick boxes' of ethnicity, heritage, disability, mental health, gender, faith, age, generation, class, family and citizenship status.
- Recognise the impact of isolation and multiple discrimination experienced by many black and minority ethnic disabled people. Disability, equality and race equality need to be addressed alongside other dimensions.
- Create safe spaces to share memories and explore identities and heritage – this can be very powerful.
- Fuse different ideas and techniques, drawing on longstanding cultural traditions as well as new arts and IT media.
- Use local opportunities to bring about wider change where possible.
- Build in time and a budget for networking locally, regionally and nationally.

The full report provides further suggestions and checklists for funders and others.

About the project

Becca Singh is a freelance researcher and consultant on diversity and equality. She used interviews, participatory observation and documentary analysis to draw out themes and lessons from the four projects. An event was held to bring the projects together to test out initial findings and identify further learning.