

Involving black disabled people in shaping services

The involvement of users has been actively promoted within social care as a way of developing more appropriate and responsive services, bringing benefits to both service users and providers. There has, however, been a noticeable lack of involvement by black disabled people. Research undertaken by Rachel Evans and Martin Banton of the Council of Disabled People Warwickshire with support from Coventry University's Centre for Social Justice explored one organisation's experiences in developing the involvement of black disabled people. The research found that:

 Both users and professionals thought it was important for black disabled people to have opportunities to be involved in consultation, evaluation and policy development. However, it was just as important to address practical issues (prioritised by users) like providing good physical access, a comfortable venue, language support and transport.

 Users and professionals identified many barriers to involving black disabled people:

- racism within white organisations and discrimination against people with disabilities within black organisations;
- lack of funding for specific work with black disabled people;
- short-term and insecure funding arrangements which do not allow ongoing outreach and development work;
- unwillingness of some organisations to divert funds from their original remit of race or disability, or prioritise work that they see as marginal to their core interest.

 The experience of the Council of Disabled People Warwickshire suggested four key elements had to be in place before practical work could begin:

- committed people to take the work forward;
- pro-active attitudes and an awareness of the issues across the organisation;
- recognition of the impact of multiple oppression;
- an organisational structure that supports different types of involvement and movement between them.

 Users and professionals identified priority actions for organisations wanting to develop black disabled people's involvement:

- employing a black worker;
- training all staff on race and disability;
- consulting with black disabled people about their needs;
- undertaking some direct work with black disabled people (and their families, if this is what the disabled person wishes);
- joint-agency working across black organisations and disability organisations.

Introduction

Black disabled people have frequently found themselves falling between services for black people and services for disabled people. This divide is often mirrored in the priorities and remits of funding bodies and voluntary and statutory agencies, as well as in the gap between the disability movement and the race equality movement. This is the context which gives rise to the low numbers of black disabled people involved in developing services.

The Council of Disabled People Warwickshire (CDP) is a community organisation run and controlled by disabled people within Coventry and Warwickshire. Black disabled people (predominantly Asian and African Caribbean) are involved at all levels within the organisation, for example as service users, paid workers and volunteers. This research explored CDP's experiences in developing this involvement since the early 1990s.

Differences in user and professional views of involvement

Both the black disabled people who use CDP's services ('users') and people involved in a paid or voluntary professional role ('professionals') described similar opportunities for involvement by black disabled people. These could be grouped into five categories: using services; consultation; direct work (e.g. voluntary or paid work in service delivery); strategic development; and decision-making (e.g. management committee membership). It was seen as unhelpful to present these as a continuum or ladder since this might imply that some types of involvement were less valuable.

Both users and professionals identified a range of benefits of user involvement: meeting others in similar situations and relieving boredom and loneliness; language support to get help with form filling and dealing with other service providers such as GPs; an opportunity to share and learn from each other's experiences; giving each other practical and emotional support; being able to inform and educate workers about their specific experiences and needs; access to information, education and training; and the development of skills, confidence and self-esteem. In addition, professionals emphasised the benefits of user involvement for service evaluation and development.

Everyone agreed it was important to respect people's rights to make choices about the type of involvement they have, whilst ensuring that the supports and structures are in place to enable people to be involved whenever and however they wish.

Barriers to involving black disabled people

Funding

Both users and professionals felt strongly that there was a lack of dedicated funding for work with black people generally and particularly for work with black disabled people. They felt that:

- Many funders did not recognise a need for specific work with black disabled people or the additional resources this required. Black disabled people were not seen or heard enough to be a funding priority for anyone.
- Restrictions on funding meant some organisations felt forced to focus on their original remit of either race or disability.
- Where funding was obtained, it tended to be for short term projects, which did not allow time for: the outreach and development work that needs to be done; outreach to find black disabled people; time to build relationships and trust with individuals (sometimes also with families); and time to build partnerships with other organisations.
- Inadequate time and resources were often coupled with unrealistic expectations that projects and workers would achieve quick results. When these were not delivered, organisations could be seen as failing, making it harder to secure further funding.
- Insecure and short-term funding arrangements also meant projects had to keep going back to the beginning in identifying and engaging with black disabled people.

"Someone has got to have a remit to do it you know ... because it's not just going to happen unless someone's actually resourced to do it, and funders don't want to resource it." (Professional)

Lack of appropriate mainstream services

Users felt strongly that even where they knew of services, they were often not appropriate, for example for meeting language or cultural needs. This prevented them from using or becoming involved with those services. Where there were specialist services, people felt they tended to focus either on non-disabled black people or on older black disabled people. As black disabled people did not use mainstream services, they were not visible and therefore not recognised as a specific group.

It was recognised that some families gave the impression that they did not need help or services. However, many people felt that white service providers used stereotypes about black families as an excuse not to provide services for black disabled people:

"They tend to give white people more support in the way that they're living on their own, but because you're living in a family, and you've got a lot of family, they always think that you've got a lot of support, so they just don't want to know." (User)

On the margins of black organisations and disability organisations

Professionals from different organisations were honest about the difficulties they sometimes faced in taking forward work that was seen as marginal to their core remit of either race or disability. This was partly because of funding constraints and partly because of attitudes.

"We're starved of resources ... and our original remit is race, and then I say, 'Well, I want to do a black disability conference.' People look at you and say, 'Well, is that a priority?'" (Professional)

Racism, discrimination against disabled people and multiple oppression

Many users spoke of experiences with a range of white service providers where they had been denied access to services and resources or given less information than their white counterparts. They mentioned stereotyping and low awareness of cultural issues within some organisations. Both users and professionals linked racism with experiences of being ignored or dismissed.

"We think our suggestions will not be accepted. What white people say is done. We remain quiet and do not make any contribution." (User)

Most people felt there was a greater acceptance of disability within white and black communities than there was of race within white communities. They also felt that a stigma was attached to disability within some black communities. It is important to recognise here that people have different levels of awareness of race and disability issues, and that attitudes vary between and within black communities, as in white communities. Significantly, the lack of services and awareness-raising work on disability in black communities when compared to white communities was seen as a contributing factor to the stigma of disability in some black communities.

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

"I am subjected to racism, I am subjected to harassment, I am subjected to abuse and I have nowhere to go." (User)

Physical access

Users felt there was often a lack of appropriate facilities, particularly in black organisations' buildings and in community meeting places (such as temples), and that so-called accessible facilities were seldom accessible for people with different impairments (such as visual impairments).

Confidence and experience

Participants thought it was clear that some black disabled people were strong, confident, and articulate, but that others lacked experience and confidence. This might have an impact on their ability and willingness to become involved. Participants felt that being confident was not about speaking 'good'

English or behaving in a certain way, but about the confidence that comes from positive experiences and opportunities. These experiences might be lacking in the lives of some black disabled people.

General strategies for involving black disabled people

Participants identified over 20 strategies for involving black disabled people (see Box 1 for examples). Both users and professionals felt that involving black disabled people in consultation, evaluation and policy development was important. However, the most important issue for all users was the provision of an accessible and comfortable venue, and yet strategies relating to physical access, comfort and transport were rated no higher than eighth by professionals.

Box 1: Some strategies for involving black disabled people

General approach: e.g. recognising multiple oppression, raising awareness of issues, joint agency work and having black and bilingual workers within the organisation.

Practical issues: e.g. using various communication techniques (especially audio tapes), providing transport and an accessible venue, meeting cultural needs and holding regular meetings/events.

Ways of working: e.g. building relationships with individuals and families, having a dedicated role to develop the work, providing separate services for black disabled people and active outreach.

User involvement: e.g. providing varied opportunities for involvement including consultation, evaluation and policy development, offering training and respecting the skills that black disabled people have.

Some of the strategies generated considerable discussion and differences of opinion.

Building relationships with individuals and working with families

There was general agreement that taking time to build relationships was vital. The controversial question was who to build those relationships with. For some people it was the whole family. For others, the disabled person was seen as having separate rights, their own identity and interests:

"Why go and talk with the husband and the mother and the father?... If that was a white disabled person, would that argument hold?" (User)

There seemed to be a consensus of opinion that organisations should be willing and able to work with the whole family if that is what the user wants, but it should not be assumed that this is what the user will want. Also, where work does involve the family, the individual black disabled person should still remain the focus.

Mainstream services or separate provision

Both of these were seen as positive strategies for developing involvement. Many users said they would like a choice. Some felt there was a need for separate provision, in the short term at least.

"Do you see, by ... [rejecting separate provision] we could actually shoot ourselves in the feet? The thing is ... we say go mainstream, and then nothing changes, because nothing will change for years ..."
(User)

An organisational agenda for change

Participants agreed that there were four essential ingredients that needed to be in place before an organisation could begin to develop work with black disabled people (see Box 2).

Box 2: Essential ingredients for change

- committed people to take the work forward;
- pro-active attitudes and awareness of the issues;
- recognition of the impact of multiple oppression;
- organisational structure that supports different types of involvement and enables people to move between them.

With this foundation in place, and given that many organisations work within tight funding constraints, the following priority actions were identified:

For white organisations:

- appointing black and bilingual workers.

For black organisations:

- starting some direct work with black disabled people, with a commitment to ongoing and regular consultation and evaluation about services.

For both:

- joint working with other organisations to combine expertise on both race and disability;
- training on race and disability (multiple oppression) for all staff;
- addressing practical access issues (buildings, language support, transport, etc).

Conclusion

This research identified many reasons why black disabled people might not use services or become involved with organisations. The impact of structural, cultural, individual and internalised oppression can be seen in all the barriers that people described. Funding bodies and organisations – including mainstream providers of health and social care services, and organisations with a focus on race or disability – could be said to have a responsibility to remove these barriers and to enable black disabled people to have more power and control in their lives and in the services they use.

About the project

The research was undertaken by CDP, supported by Coventry University's Centre for Social Justice. It involved semi-structured interviews and focus groups with 35 people who had been involved in different ways with CDP's work with black disabled people. Of the participants, 63 per cent were black disabled people and all but one of those were also users of CDP's services. 97 per cent of the participants were black.

How to get further information

The full report, **Learning from experience: involving black disabled people in shaping services** by Rachel Evans and Martin Banton, is published by the Council of Disabled People Warwickshire (price £10.00 plus £2 p&p). It is available from the Council of Disabled People, Fordsfield, Bury Road, Leamington Spa, Warwickshire, CV31 3HW, Tel: 01926 420702. The full report includes action planning and team activities to explore within organisations the issues raised by the research. For more information about this research please contact Judith Stephenson, Director, CDP at the address above.