

# Something to do

The development of peer support groups for  
young black and minority ethnic disabled people

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# Acknowledgements

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# Terminology

black	The word black (lower case) is used in this report to define people who suffer racism because of their skin colour. In the context of British society, we refer to those of African, Caribbean or Asian origin.
deaf/Deaf	The term deaf/Deaf is used as in Ahmad et al (1998), which is drawn from the work of Padden and Humphries (1988). The word deaf (lower case) is used as a generic term to describe people with different forms of deafness. Deaf (with a capital D) is used as a self-definition based on the use of sign language, membership of the Deaf community and recognition of Deaf culture.
disabled	In this report we refer to the social model of disability, that is, having a physical, emotional or learning impediment that requires the provision of specific facilities to enable the individual to fully participate in, contribute to and benefit from society, both in their personal life and in exercising the full rights and responsibilities of citizenship, in so far as they choose to do so.
minority ethnic	The term minority ethnic is used to describe a group who are a minority in a particular situation or country because their ethnic origin is different from that of the majority community. In Britain it is often used to describe communities whose origins are in the Caribbean, or Asian or Africa. It is also sometimes used to describe people whose origins are in Eastern Europe or Ireland.



# Introduction

“... you have everyone around you who needs you, and when you feel down in yourself you have someone around.”

“I meet different people and make people laugh ... have a laugh and make new friends.”

“You can’t stay at home, 48 hours in the house.... Something different to do.”

In a previous research project in 1998 (Bignall and Butt, 2000) we spoke to young Asian, African and Caribbean Deaf and disabled people about their lives, experiences and plans for the future. Among other things, the young people talked about being lonely. The day centres or Deaf groups they went to were often full of older people. They wanted to meet other young people who were similar to them – who were black and disabled – but they had no idea where to find them.

We knew there were some peer support groups for young black Deaf and disabled people and decided to find out more about them. What we learned is presented in this report.

## Background

Many studies have raised concern about the emotional and social well-being of young disabled people. They often have little chance to meet people outside their families, which means they are unable to form friendships in the same way as their non-disabled peers. Work by the Mental Health Foundation (1996), for example,

found that young people with learning difficulties spent most of their time with people not chosen by them – usually family members and staff at schools or day centres. Likewise, Morris (1998) highlights the importance of social relationships to young disabled people living away from their families, yet, she points out, many do not have the peer-group relationships enjoyed by other young people and often refer to key workers as ‘friends’ or ‘best friends’.

Other studies have examined young disabled people’s social networks by considering peer support and membership of groups that provide such support.

### *What is a peer support group?*

A peer support group is a group that provides emotional and social support to its members. Studies have shown that membership of these groups helps the personal development of young disabled people, providing them with added skills, increased self-esteem and confidence, the opportunity to share experiences and discuss concerns about their impairment or identity, and the chance to make friends. Hence belonging to a peer support group is seen as empowering by young disabled people (Russell, 1998).

However, the opportunity to experience this kind of support is not necessarily open to all young disabled people. There is little known, for example, about young black disabled people’s opportunities for peer support.

## *Peer support groups and young black disabled people*

A central concern for young black disabled people is the discrimination they can experience at mainstream support groups and day centres. Young black people with learning difficulties, for example, feel excluded from mainstream learning difficulties groups because of their 'blackness'. At the same time, they find it difficult to make friends with other young black people because they are 'different' (Amoa, 1997). It comes as no surprise, then, that young black disabled people say they have few or no friends, and lack opportunities to develop and sustain friendships. They mention racist name-calling and being treated differently at day centres. Some decide to stop going. Furthermore, there is a lack of information about other support groups. A number of young black disabled people have therefore started to establish their own groups to meet their need for emotional, social and peer support (Bignall and Butt, 2000).

The benefits of peer support groups for disabled minority ethnic individuals include an end to social isolation, bringing people together who share the same experiences or concerns, and providing information, emotional support, advice and assistance (Wann, 1995). Sometimes these groups emerge partly in response to the failure of mainstream services to address cultural and religious needs. One study found that Asian and Caribbean Deaf people organised their own means of meeting their needs through social-support groups. These groups allowed the open discussion of social and cultural issues, provided role models, enabled the growth of networking and the development of friendships, and assisted in developing self-esteem. Furthermore, "being part of a social group with people of a similar background meant that Deaf people could discuss sensitive issues such as marriage and family life" (Ahmad et al, 1998, p 51). Attending these groups, then, was an empowering experience for minority ethnic Deaf people.

The literature suggests that peer support groups for black Deaf or disabled people are set up for distinct reasons – to provide different and specific services as well as the opportunity to develop friendships.

## **The research project**

Our interest in this project centred on how these peer support groups develop and are organised. Our research set out to learn more about a number of issues relating to the development and maintenance of peer support groups for young black disabled people.

### *Using this guide*

This guide provides an overview of young black Deaf and disabled people's experience of peer support groups. Using members' own words, the guide reveals to others what a peer support group is like and what it can do for those who join. It gives information on how the groups were set up, how the groups are organised, and why it is important for such groups to exist. There is also a checklist for those wishing to start their own peer support group.

### *Working with the peer support groups*

Five groups agreed to work with us in this project. All but one of the young people we met were over 16 years old. They asked us to use their own names and the names of their groups when writing this report. The group profiles are outlined below.

## **Group profiles**

### *African Caribbean Leisure Group*

This is a Leeds-based group of African Caribbean young people with learning difficulties. It has been running for three years.

- *Membership*

The group has quite a large membership, but only 8 to 10 members attend each session. All are aged between 18 and 25. We spoke to 10 members: Andrew, Beverley, Christopher, Darren, Dawn, Errol, Gloria, John, Michael and Qasim.

- *Activities*  
The group meets weekly and sessions focus on leisure activities. It has a working ethos of 'freedom of choice', where all members are able to express their choice of action. The group undertakes activities that develop independence skills, enable participation in the local community, and explore different ways of empowering members.
- *Support*  
A development worker, session workers and a number of volunteers support the group.
- *Funding*  
The group receives joint funding from a number of different agencies.

### *Association of Bradford Deaf Asians Women's Group*

This is a group of Asian Deaf women who are part of a larger Asian Deaf association. The association has different weekly sessions for young men and women. The women's support group has been going for about five years.

- *Membership*  
The overall group membership is 25. This includes a group of younger girls aged 6 to 12, and an older group aged 12 and above. We talked to the latter group. Twelve young women regularly attend this group session. Most are aged between 16 and 24, with the youngest being 13 years old. Members we spoke to were: Nageena, 13, Neelam, 16, Shahika, 17, Debbie and Fameeda, both 18, Tahira, 19, Shazana, 21, Shubana, 22, and Kaneez and Sureya, both 25.
- *Activities*  
The young women meet weekly. They run group sessions, where they discuss health and education issues. They also organise social and religious events, activities and trips. As the association shares a venue with the local youth services organisation, the group has access to facilities such as a TV, snooker tables and kitchen area.
- *Support*  
There is assistance from two development officers. The female development officer facilitates the women's group.

- *Funding*  
The association is funded by joint finance from various sources, including the local authority.

### *Asian Deaf Young Women's Group, Coventry*

This group has been running since January 2000. However, its origins go back several years to a previous Deaf women's group.

- *Membership*  
The group comprises six young women aged between 16 and 25: Mahmuda, Maria, Nirmal and Safeena, all 20, Sobbia, 21, and Shazia, 24.
- *Activities*  
The group meets fortnightly. Each group member has their own development programme, which they work towards achieving. The main functions of the group are to provide positive role models, information and advice, to enable members to learn about religion and culture, and to share common experiences. This group is in the early stages of development and recent work has focused on identity. Activities include trips and group discussions around health and religion.
- *Support*  
Support comes from a female development worker from the local social services department.
- *Funding*  
The local social services department funds the group.

### *Black People First Group*

This Swindon-based group is part of a People First organisation, but has a separate identity.

- *Membership*  
The group members are men and women with learning difficulties, aged 20 to 30. Ten people of Asian, African and Caribbean backgrounds are members of the group, but only five attend on a regular basis. Their names are Cheryl, Danny, Jason, Navine and Satwinder.

- *Activities*  
The group meets weekly and sessions focus on social and development activities. All sessions are in-house, although the group is trying to hold more outside activities. The group has discussions, invites speakers, holds religious celebrations and learns about different black communities and cultures. Its members have recently completed a video project about the group.
- *Support*  
There is a support worker who facilitates each group session.
- *Funding*  
The group has been running since 1998 with funding from Comic Relief. It is now seeking further funding.
- *Support*  
Support comes from a development worker from the Tower Hamlets Disability Advocacy Network.
- *Funding*  
The group receives funding from different sources.

### *Tower Hamlets Self-Advocacy Group*

This is a London-based self-advocacy group of 14- to 20-year-olds. The group was initially set up as a mainstream group for young disabled people with a range of impairments, but has become predominately attended by Caribbean and Asian young people. The group has been running for two years, with members attending at different intervals.

- *Membership*  
The seven regular group members are: Balal and Koyes, who are both Deaf and aged 16; Ismail and Mizan, who both have learning difficulties and are aged 18; and Nahida, Scott and Sarena, who all have multiple impairments and are aged 16, 17 and 18 respectively.
- *Activities*  
Group members are young people attending a special school. They meet weekly outside school lessons. Their sessions centre on discussions and activities around empowerment, identity and developing self-esteem.

# The peer support groups

The main aim of the five peer support groups is to provide emotional and practical support to young black disabled people. Although the nature of each group differs from one another, all have a vision of why the group exists and where it is going, and all have values that underpin how the group works. However, the focus of each group is very much grounded in the activities its members undertake.

## How they got started

All five groups emerged as a result of the initiatives of disabled people's or Deaf people's organisations. The Tower Hamlets Self-Advocacy Group developed through a Disability Advocacy Network project, which set out to promote self-advocacy among young disabled people. The Asian Deaf Young Women's Group in Coventry was established through the developmental work of a Centre for Integrated Living. Similarly the African Caribbean Leisure Group was set up through a voluntary disability organisation aiming to empower young people with learning difficulties by developing their independence.

Young disabled people themselves initiated two of the groups. Asian Deaf women in Bradford demanded that their organisation set up a group just for women. Black people within the mainstream learning difficulties organisation, People First, also wanted to form their own group, and reach other black people with learning difficulties in their area, hence the Black People First Group evolved.

## What they do

The young people told us what they did within their groups:

“Play pool, games, food and whatever.”

“Trips, we do trips a lot.”

“Watch videos, speak, sometime play the drums, sing.”

“We talked about friendship, sex ... condoms, Mile End Park [project].”

“Usually we learn about things about experience, things like our confidence and Asian things abroad. Things about any worries, any concerns, problems with religion.”

Group sessions provide the opportunity to meet with other young black disabled people, share information, catch up with friends, or simply spend time together.

## How they are organised

As the group profiles reveal, four of the groups are impairment-specific and just one is for young people with a variety of impairments. Three of the groups are ethnicity-specific, with the other two catering for all black people, regardless of ethnicity. Two are women-only groups, and three are for both men and women.

## Ethnicity

Even though all groups are very clear about being 'black' groups, the Asian Deaf Young Women's Groups welcome young Deaf women who are white, or from other ethnic backgrounds.

This may be due, in part, to their confidence about their own culture and religion. Both groups stress that those from other ethnic backgrounds must be very aware of their group's Asian identity and its centrality to group meetings – the Bradford group, for example, explained that they welcomed people from other ethnic backgrounds as long as they respected the group's identity. People from different religions are said to be welcome as long as they do not try to convert the Asian group members and work within the ethos of the group.

It is also likely that these groups welcome others from different ethnic backgrounds because at times support was needed around issues of impairment and disability rather than issues of ethnicity. Deafness may sometimes be more of an issue than being Pakistani, Muslim, or Asian.

## Gender

Sometimes, gender is very important to the role and identity of the group. This is especially true of the Asian Deaf Young Women's Groups.

Discussions with these women confirmed that having a group specifically for Asian Deaf women was an important attraction. The Bradford women raised the difficulty of attending a mixed-sex group. Their group was originally established for young Deaf Asian men and women, but as time went on this became problematic. According to one young woman:

"... slowly the group expanded and started getting bigger and bigger and bigger. It got so big that we all felt that we had specific women's issues we wanted to talk about, so it's better to have it separate. So we demanded the boys' and girls' group was separate."

The gender-specific nature of the groups is also used to manage parental consent for the young Asian women to attend sessions (see 'Parental support', Chapter 4).

Religion and culture may be major determining factors here, as women in the other peer support groups do not feel that attending mixed-sex group sessions is a problem. One young woman in the African Caribbean Leisure Group is the only woman at most of the meetings, but this does not deter her from attending.

## How long the group has been running

The length of time that a group has been running has an effect on its level of development. The Asian Deaf Young Women's Group in Coventry had been going for six months at the time of their involvement in this research project. They were at the 'storming' and 'forming' (Gibson, 1995) level of group development – establishing their aims and norms (rules and expectations the group wants to set), while dealing with the individual and emotional needs of members. The need for information from the group was the main concern for the young Deaf women involved – information about both their impairment and their ethnicity. This group spent a lot of time talking about the difficulties they experienced within their families, and about coming to terms with their identities as young Asian Deaf women. As one young woman told us:



“Well we’re here to learn about Asian culture and Asian Deaf women, so it’s sharing that information really. So it’s really talking about the reason why we’re here ... talking about religion, being Asian, being Deaf women. So it’s information about culture, so that we know what it means and that’s the point of the Asian Deaf Women’s Group. That’s what we’re here for. It’s almost like a course really. It’s like being on a course, getting all that information.”

In contrast, the African Caribbean Leisure Group had been running for three years and members were clear about the focus of their group – to develop independence and empowerment through a variety of leisure activities. This group’s values were very well defined. Their activities tended to be less focused on emotional support and more about coming together as a group to visit different leisure venues.

It seems that the length of time the group has been going is important in terms of the focus of the group. Unlike the more established groups, those in the early stages of development are still trying to define themselves by developing structures, encouraging membership and active participation, and refining their group focus.

## Factors that affect how peer support groups work

The young people talked about various factors that affected their group. These centred on membership and activities.

### Membership

An important part of a group’s development is to increase the number of young black disabled people attending their sessions and benefiting from the services and support they provide.

Those at the Black People First Group, for example, want to tell others about their group. They have produced a video of what they do, and placed public notices in local papers to encourage more young black disabled people to join them. The Asian Deaf Young Women’s Group in Bradford have not only increased their membership, but they have also changed the

nature of their parent organisation by insisting on a gender split, as discussed earlier.

For the Tower Hamlets Self-Advocacy Group, changes in membership have adversely affected their cohesiveness. They have seen a constant change in membership over the previous two years. Most of the young people we talked to had attended group sessions on an intermittent basis throughout this period. Only three appeared to be regulars and were able to comment on the group’s development.

### Activities

The benefits of peer support groups for the majority of these young black disabled people have come from participation in group activities. Most of the groups see any changes in activities as positive. As a member of the Asian Deaf Young Women’s Group in Coventry suggested:

“... the group changes in terms of people, like what culture they’re from, and learning the differences between languages. And we’ve learnt how to do travel training – how to use public transport.”

Only a few members voiced dissatisfaction with their peer support group, and this tended to centre on the activities being organised. Often there would be at least one person in a group who wanted changes in the type of activities on offer. A woman in the African Caribbean Leisure Group, for example, wanted a greater variety of trips rather than predominately pub visits. Others also wanted to expand the range of group activities, perhaps going on more trips and to more exhibitions. A few people mentioned that they wanted their group to meet more often, partly to alleviate the loneliness they felt between sessions. But most people seemed happy with the regularity of their group sessions, particularly where more meetings would result in other concerns – such as having to spend more money (see ‘Money matters’, Chapter 4). On the whole, however, members did not raise issues they were unhappy with. Rather, they discussed areas they would like to see improved.

# What peer support groups mean to members

We asked the young people to describe why they went to group meetings and what their group did. Their responses are outlined below.

## Why they join

Members gave a number of reasons for attending the groups. Here are just some.

### *To meet other people*

“I’d say just meeting different people, someone else to talk to.”

“Just meeting people really. I’m not an outgoing person. I’m quite shy.”

### *Something to do*

“[To] get away from the four boring walls ... it’s nice to get out and meet friends.”

“You can’t stay at home, 48 hours in the house. You don’t come to the meetings or go out, you don’t know what’s going on. [It’s] something different to do.”

### *The group is different to other support groups*

Some were initially members of other groups but did not feel comfortable in them and so joined their present group. One Deaf woman described the difference between a mainstream Deaf group and the Asian Deaf Young Women’s Group:

“The behaviour was bad, they were troublemakers ... and I just wasn’t happy in that environment... Well it’s mostly white. There are a few Asians there and they do mix but it’s different.”

Some members explained that there were no other groups like theirs. It is likely that this influenced their regular commitment to the groups.

### *Somewhere to talk to other young black disabled people*

“[It is] a good opportunity to talk to [the supporter] and the group.”

“Because at home – [I’m] just bored ... talking with my family. It’s not their first language and I can’t relax and talk [BSL signing] to them properly.”

### *Feeling comfortable*

“Because I’m confident with Deaf people. I’m able to sign, and with women. I feel more comfortable with Asian women in particular. I’m able to say [BSL sign] what I like.”

### *To learn new things*

“To have information about health, about trips – you can get information about everything you need to know about. If [the group supporter] didn’t tell us the information about things then we’d be brain-

dead. We wouldn't have any information. We wouldn't develop."

### *To have fun*

All groups allow their members to have fun and provide an environment where they can enjoy themselves. How this has been achieved varies from group to group. One member of the Black People First Group, for example, said he enjoyed "making the tea and cutting things with scissors ... I like throwing paper in the bin..."

## How peer support helps

Members mentioned many benefits of being part of a support group. These are discussed below.

### *Learning about ethnicity*

For many of the young people, their group provides one of the few opportunities they have to explore their ethnicity in more detail. They want answers to questions about religion and they want to learn more about their own cultural background. Those who attended the Black People First Group have a clear recognition of their own and each other's ethnic background. As one man told us, "It is important because we have people from different countries".

Young Asian women told us they have discovered more about their ethnicity through being part of the group. They recognise they belong to a 'Deaf culture' but also want information and a better understanding about their other 'cultural' identity. As one Asian woman said:

"Because my mother and father don't know sign language they can't teach me about my own religion and my own culture. They teach me rather about the Pakistani culture, which is different from the majority of the religious teaching, and I don't know what to choose from. I don't understand things because they don't know my language. Asian culture is different and the Deaf culture is different. So they haven't learnt to accommodate my religious teaching, my cultural teaching, which is Deaf culture. They don't know about my background. I have a different background. They don't understand me. It's different with their culture. We've got Deaf culture, they've got hearing Asian culture. And they have their particular understanding of what religious and cultural issues [are] according to their culture."

Groups have therefore become the forums where questions around ethnic identity are discussed. Another Asian woman relates:



“My mother told me – she’s been teaching me about things – about my own religion and culture. And I didn’t understand it. It just wasn’t relevant. And then through talking through [things with] the other girls in the group and talking to [the development worker] I’ve started to understand things.”

Group activities help the young people with learning difficulties to think about ethnic identity. Take the Celebration Day activities of the Black People First Group:

“I enjoyed telling people where I’m from and listening to people, where they come from.”

“Someone came in to show them how to put on a sari.”

Groups also make efforts to express ethnic identity. For example, the African Caribbean Leisure Group has carefully selected a pub to meet in, which plays reggae and soul music. For others, it is a matter of choosing where and what they eat on outings.

Closely associated with this interest in ethnic identity is the desire to belong or feel comfortable. It is evident that many of the young people attending the groups are more ‘at ease’ because they are with people of their own ethnic background. Recounting her first time at the Asian Deaf Young Women’s Group in Coventry, one woman said:

“... the fact that it was an Asian women’s group made me feel good. We looked at the history of Asian families, about our parents, and finding out about each other’s families.”

A woman from the African Caribbean Leisure Group made comparisons with other support groups she had been to previously, which were attended mainly by white people:

“Well this group, the only difference is all black faces not white faces.... I feel better mixing with my own.”

It seems that peer support groups for young black disabled people can provide various means of

learning about their own ethnicity and that of other people.

### *What it is like to be a black Deaf or disabled person*

The Tower Hamlets Self-Advocacy Group offers its members the opportunity to explore issues that affect them as young disabled people. Individuals from this group explained:

“[We] talked about what it means for us to be young disabled. Work around identity.”

“[We] talk about how we’re feeling and whether we’re happy.”

Their activities included a project exploring the social barriers that affected them.

Both ethnic identity and their identity as disabled people are important to young black disabled people, although one or the other can come to the fore at different times. The significance of ethnic identity is particularly evident in the Asian Deaf Young Women’s Groups, as women in the Coventry group told us:

“We talked about different religions in the Asian community and the women – all the different religions.... We wanted to find out what our religions entailed, whether our religion was strict or not, so it’s very interesting to find out from each other.... It’s a very cultural group and we talk about the different cultures as well within the Asian community. And now I’m a woman we talk about, you know, being a woman in the Asian community. And about being Deaf too!”

### *Building confidence and self-esteem*

The majority of members speak of the confidence they have gained since they started to attend the peer support group. Some of this confidence stems from being able to express themselves comfortably in a forum where others want to listen. Confidence has also developed as a result of the new skills they have acquired. Members of the African Caribbean Leisure Group speak of the independence they have developed through attending the group. Travelling to sessions by

themselves is one example of this (see 'Transport considerations', Chapter 4).

Those at the Self-Advocacy Group emphasise their self-development in discussions about independence. They also talk about how they have learned to listen to and appreciate others. One activity of the Coventry Asian Deaf Young Women's Group encouraged the young women to plan a route by train and travel themselves. This was a great opportunity for them to express their independence, and so develop their self-confidence. The teamwork involved also helped develop consideration and respect for others.

### *Feeling lonely and getting emotional support*

For some people, the alternative to attending their support group is being at home on their own. As a Deaf woman explained:

"... when you're at home, you're all on your own, you're lonely, and I want to be equal to the hearing world. The hearing world gets out and about ... they get lots of insight into different issues. When I come here I get that same insight because there's a link here between the hearing and Deaf world, but it's appropriate to the Deaf culture and the Deaf community. And I can also share experiences with Deaf people about how they're feeling."

Groups are sometimes the centre for emotional support and often provide the environment for friendships to develop. These friendships enable the young people to support others by talking about their experiences. Talking to each other is something members recounted again and again as one thing they enjoyed about attending their group. Members of the Self-Advocacy Group said meetings are where "we talk about everything that matters to us". One young woman added:

"... you have everyone around you who needs you, and when you feel down in yourself you have someone around – you know what I mean?"

There is also a sense of understanding because everyone has so much in common.

### *Something to do*

Peer support groups provide the opportunity to have fun. Most people highlighted this as something that was good about being in the group. "Doing fun things" and "not being serious" were expressed in many ways: dancing, playing games, singing, playing Caribbean music, having Eid (a Muslim religious festival) parties, going on trips, going out to pubs and restaurants, and so on.

A member of the African Caribbean Leisure Group stressed the fun he had attending his group:

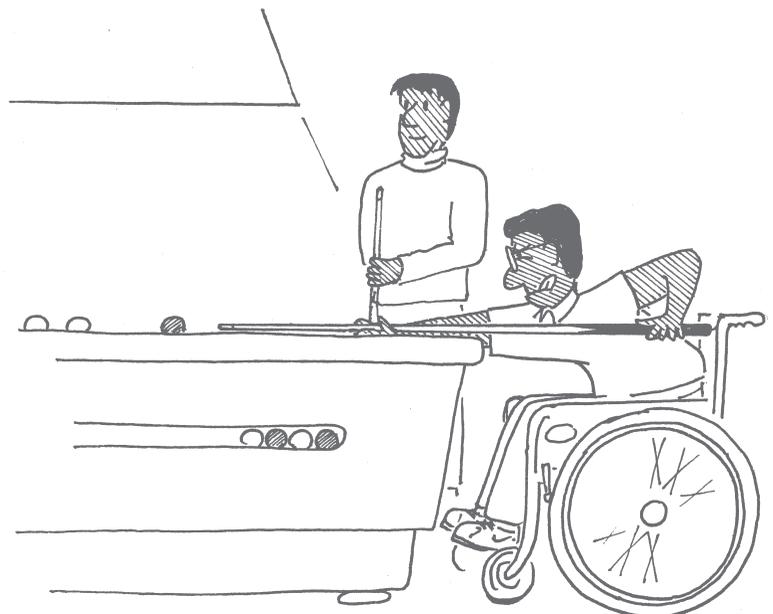
"I meet different people and make people laugh ... have a laugh and make new friends."

Others in this group spoke of the bar that they regularly met at:

"It's got good music in there, don't knock it!"

"It's got great dancers, late-night clubbing, so they make it good."

Many activities also provide members with the opportunity to learn and develop skills. Some groups give advice on how to budget money, make drinks, go shopping and use equipment.



As mentioned earlier, the focus on learning is often considered important. A Deaf woman described how attending the group has helped her to develop:

“Before ... I didn’t have a clue about what was going on. And through discussion with these girls, firstly my signs improved, and also my life skills have really improved by seeing role models of the other girls around me.”

Groups also enable the young people to go on trips both in the UK and abroad. One of the Deaf groups, for example, visited the Gaza Strip and exchanged experiences with Deaf people there.

### *Making friends and having relationships*

Attending the group provides the young people with the opportunity to make new friends and to develop these friendships outside the group. Some also see their group sessions as providing an opportunity to develop romantic relationships.

### *Friendships*

We asked members what they liked about belonging to their group. Those in the Black People First Group referred to having friends as one of the good things. As one young woman pointed out, the group provided the means of “just getting out and meeting different people” – not just the other group members but also people who had been invited to give talks or demonstrations.

For some, having friends at the group alleviates the loneliness they experience in their lives. A woman from the African Caribbean Leisure Group said she liked meeting people:

“... ’cause I don’t like living on my own. I get sometimes bored. When the letter comes and says come to the meeting and see what the people are doing, I can’t stay at home ’cause you don’t want to stay inside all the time. [I] like to do something outside as well, ’cause I’m living on my own. ’Cause I get sick and bored of watching TV...”

Sometimes closer friendships form between some members than between others. For example, two young men from the African Caribbean Leisure Group spend a lot of time together and speak to each other more often than to other group members, but the fact that they have such a close friendship does not preclude them from having friendships with other members.

The peer support groups also seem to nurture friendships formed within the group, so they can develop outside the formal sessions. This was evident in both of the Asian Deaf Young Women’s Groups. Here the young women meet for meals or trips to the cinema, or just visit each other’s houses. One woman said:

“We always meet at weekends ... sometimes we meet at my house and sometimes we just chat, go out to town, shopping, whatever.”

### *Romantic relationships*

Some find group sessions to be the main focal point for meeting members of the opposite sex. While it is fair to assume that this might be an opportune meeting point for most of the young women and men, the men mentioned it more often. The young men in the African Caribbean Leisure Group, for example, frequently remarked on the advantage of going to one particular venue where they could meet “girls”. When asked what was good about this venue, one young man said:

“Lots of girls in their short mini skirts, doing a dance. I were there all night.”

However, it seems that peer support groups don’t address the need for young people to develop romantic relationships; rather they encourage platonic relationships. This is often welcomed by the young people, as well as by their parents (see ‘Parental support’, Chapter 4). Young women in the Bradford Deaf Group, for example, are very positive about being in a girls-only environment, where relationships with the opposite sex are not an issue.

### *Group dynamics*

In all the groups, some people were more willing to talk than others and were considered the 'leaders' by other group members. In the Bradford Deaf Group, for example, two particular women would respond to points raised in the discussion and the other women then tended to agree with them. They might talk further to clarify a point, but it was essentially one of the more articulate members of the group who spoke for them all.

There are individuals within some groups who habitually assist others. Danny in the Black People First Group, for example, helps Judge who has severe learning difficulties and little verbal communication. Danny also works closely with the supporter. When asked what was good about coming to the group he told us he liked "... working with the group, helping out [the supporter] when he needs help. I like doing fun things, trying to get the groups attention and not being serious".

Overall, none of the groups appears to have any struggles or negative relationships between members.

# 4

## Learning from peer support groups

All the young people are encouraged to be involved in the organising and planning of group events and sessions. They told us about the many things that made the group run well.

### Making decisions

We asked members how they made decisions within their groups. The African Caribbean Leisure Group use planners to work out what to do at their weekly sessions:

“Well, we make different plans of what we’d like to do the following weeks. We just write them down.”

The group then votes on what they would most like to do. Other groups go through a similar process, discussing things as a group, then voting on what to do. If everyone does not make the same choice, all groups make sure that those in the minority will get their choice fulfilled at a later time. The African Caribbean Leisure Group “decide by splitting up the group” but this very much “depends on what activities” are on offer. One young man explained:

“We don’t always do the same thing, so that’s why we split up into two camps.”

An example was given of such a situation:

“Say if you want to go, let’s say, window-shopping or [do] girl’s things and some of us want to go to the movies to see ... *Batman* or *Donald Duck* or that, we split into groups. A group would go with you and a

group would come with us. That’s how we decide what to do.”

Those in the Coventry Asian Deaf Young Women’s Group use a different method. This involves giving feedback and recapping on the session they have taken part in the previous fortnight and ensuring that all members understand what has taken place:

“For example, we’re given information and then we give a feedback in two weeks’ time. We run through on things to make sure each of us understood what we did two weeks’ before. And it may be that they say, ‘Okay, we need a bit more information’, it may be on Asian cultural Deafness. So we’ll brainstorm, okay, so that we can write things down just to remind us what we’ve been through.”

If more information is required on a topic, a group member or the group supporter will follow this up and give feedback to the group at the next session.

Those in the Bradford Asian Deaf Young Women’s Group also use committees to make decisions and organise events. They planned and organised an Eid party by setting up a committee. One young woman explained how:

“We organised it. We made a list of invitees, food, [put together] a question and answer quiz – lots and lots of different things. We first made a list, organised a committee, organised where the money was going to come from so we can make profit out of it, got [a] committee together, put up pictures around the hall, balloons, set up [a] stage

and table, sent letters out inviting them to [the] gathering. About 140 people attended on the day. We were the volunteers for the day.”

She went on to relate how they decided who would take part:

“First of all somebody comes up with the idea and proposes it. And what we do is, we all sit down and say who’s going to go on the committee.”

Individuals working on the committee would take responsibility for the work by “giving ideas, organising, making lists of things that we need[ed] to do”.

Decision making, therefore, involves the young people’s ideas being heard, a vote taken and the majority choice acted on. In two groups, however – Black People First and Tower Hamlets Self-Advocacy – the onus appears to be on the group supporters to formulate ideas. The young people then make their choice from the ideas presented to them.

## Setting up rules

When it comes to making rules and deciding which ones should remain as a group rule, the young people are given every chance to voice their opinions. There are rules governing the process of participation in sessions – in the Tower Hamlets Self-Advocacy Group, for example, individuals have to raise their hands up before speaking. There are also rules governing members’ behaviour and how they relate to each other. Some examples from the groups are:

“We respect each other.”

“Not swearing.”

“We have a rota to say who makes the tea and gives out refreshments.”

All have a process by which rules were made. This usually involves some form of voting and agreement by all group members, but most members implied this was a fairly informal process. As one woman said:

“We don’t have this formalising of any sort of rules. It’s just common sense.”

It seems that being able to make rules impacts on the young people’s ‘ownership’ of the group and involvement in how the group runs. They suggested that rules were necessary to enable all individuals to participate fully in the group’s activities.

## Confidentiality

An important yet unwritten rule is confidentiality. Two of the groups ensured that members were aware that what was said at the meetings would not go any further. This provides the young people with a setting in which they are able to express themselves freely. One young man in the Self-Advocacy Group suggested that group sessions provided a “good opportunity to say things to the group and they keep it as a secret”. Keeping discussions secret is vitally important to those who attend this group.

## Generating changes

Support from the groups provides young people with the confidence to demand changes in the world outside their group sessions. The Coventry Asian Deaf Young Women’s Group, for example, had taken part in a national march promoting British Sign Language. Similarly, members of the Self-Advocacy Group were able to call a meeting to ask for changes in their school life because of their work on self-esteem and independence:

“Yeah, we had a meeting about ... the school and how to change something ... we spoke to ... the head teacher.”

The changes they wanted included:

“Play time ... more playtime.”

“More music.”

“More computers, more swimming and more books.”

The group is pleased they were able to demand such a meeting but haven't got the response they wanted from it.

One group has made changes by providing information and support to others that had a similar impairment. The Bradford Asian Deaf Young Women's Group went to Palestine to meet other Deaf and hard of hearing young people. The visit provided the group with a unique opportunity to share their experiences with others from a very different background. While in Palestine, they had also held an open day to give out hearing aids and information.

## Parental support

Informing parents adequately about the support group has implications for whether or not the young people will gain the benefits of peer support. How parents hear about the group – whether or not it is from a reliable source, for example – will influence them giving consent for their son or daughter to attend. One young woman explained how she had started at her group:

“One of the mini-bus drivers who used to drive the bus for ABDA [Association of Bradford Deaf Asians] ... is a friend of the family and he told the family about the Deaf group....”

Gaining information enables some parents to encourage their son or daughter to join a peer support group. For example, one man in the African Caribbean Leisure Group started attending the group after encouragement from his mother. He said:

“The first time I joined the group I didn't want to do anything, but now ... I've joined it, I think it's all right. It's up to the individual to do what they want to do.... My mum, she told me to try it, so I tried it.”

However, gaining parental support to attend group sessions is a particular concern for the Deaf Asian women. Parents' reluctance stems from a lack of knowledge of what the peer support groups are about. There is also concern that the group is an environment where their daughter will be mixing with men. Many of these young

women have to justify their group attendance in order to get their parents' permission to go. The groups achieve this in various ways – such as providing clear information (often in Asian languages) about the group and what will be happening at each session. As one young woman explained:

“My mum and dad do listen to me, and see the letter [the support worker] sends to me. And they've read it. My mother read it and she said fine, you can go....”

As mentioned earlier, the Bradford Asian Deaf Young Women's Group separated from a mixed group to form a single-sex group, which has alleviated the concern of some parents. As one young woman explained:

“Your parents [are] gonna be happier if it's separate, 'cause they might think, they're gonna start girlfriend/boyfriend relationship. The problem is getting permission from your parents. So I'd rather have my social time and be able to chill and relax where it is [a girls'-only environment].”

One of the young women from the Coventry group used to go to a Deaf centre, but told us:

“I stopped [going] at 18. My mum and dad thought I was looking for a boy. They didn't trust me and they didn't like me being out late in the evening.”

Her parents respect the fact that she now attends the Asian Deaf Young Women's Group, however.

The cultural appropriateness of the groups enables some parents to encourage their daughter's participation:

“I'm allowed to come if it's an Asian group, so it's where I can access learning within an environment where my parents will let me.”

The timing of meetings is also crucial to parents and their perception of the group:

“... 'cause it was in the afternoon from 2pm to 4pm, she said I can go.... They're happy for me to go.”

However, for one of the Deaf women, gaining parental consent is not a significant issue:

“My family accept that I go out ... and they’ve accepted that I had freedom. And they’ve never been strict and they allow me to go with my friends. They said, fine you can go out ... they are quite happy for me to go out.”

## Somewhere to meet

We talked to members about how having somewhere to meet affected the group’s progress. Only one of the groups – Black People First – had the permanent use of a room they could call their own. All the other groups met at a regular place, but this was not a venue assigned to the group.

The Bradford Asian Deaf Young Women’s Group has been meeting for several years in a building they share with the local youth centre. While this has given the young women a consistent location, which allows them to make necessary travel arrangements, they still feel the need for a place of their own. One member said:

“This is the centre that we rent out. We want a centre of our own. We want to own a centre. I don’t like this. I don’t like having to share a centre with other people. It’s not wheelchair-accessible. It’s all these stairs.... [We] want a centre with a completely flat ground.”

As the above comment implies, a group’s venue can affect the individual’s sense of belonging to the group. Having a group identity is not just about what is shared by members in terms of ethnicity, impairment, background, and so on. The practical arrangements also enable the group to be identified by its members and by other outside bodies.

It is likely, therefore, that having a stable venue will influence individuals’ participation and morale. The Coventry Deaf group has yet to find an appropriate, permanent venue. Until recently, they met in a library, in a room used by young children, where they had no access to toilets or drink-making facilities and faced many interruptions. As one woman explained:

“We’ve moved here [to a family centre] because at half three loads of people come into the library and it’s very distracting ... people are kind of looking around and saying, ‘Oh someone’s looking at me’ and [the supporter’s] saying, ‘Can I have your attention?’. So it’s quite difficult for [her] to get people’s attention in the library.”

In their new venue at the family centre, the group have their own food and toilet facilities, although this is not yet a permanent arrangement.

Similarly, the Tower Hamlets Self-Advocacy Group, who meet in their school, have experienced several room changes according to which rooms were free on the school timetable. Until the school term, when we talked to the group, they had met in a room that they had been able to decorate themselves, putting the name of the group and many of their activities up on notice boards. They then moved to an uninviting room, which was partly used to store equipment. The group supporter noted a change in group morale.

For the African Caribbean Leisure Group, having a stable venue is not quite so important. They meet at different leisure venues, including one bar which they frequent on a regular basis. However, the group still wanted a place to meet and plan their sessions. When we spoke to them, their usual meeting place was being refurbished.

In spite of the difficulties that some groups face in finding appropriate venues, they still meet on a regular basis – sometimes in members’ homes – because of the vital peer support they provided.

## Working with supporters

The way the groups work with supporters varies between groups, and seems to have a significant influence on their development and purpose. Some of the young people explained how their group had moved on as a result of the effort put in by the supporter. The Bradford Asian Deaf Young Women’s Group, for example, told us how they had developed personally and how their supporter had also changed. When discussing how they accessed information about religion and culture, both in their families and in the group, one woman said:

“... here [in the group] we find we get that information because [the supporter’s] aware of Deaf culture and how to adapt religious teaching into Deaf culture, not bring in [the] Pakistani or Asian perspective.”

The supporter started with no British Sign Language skills and has gradually improved, enabling more communication with the young women. She has steered the young women into exploring their identity, their needs and how they want their group to develop. With the aim of reducing her own input, she has supported the women to take on more responsibility for the group’s organisation and activities. At present, she is still working with the group but taking much more of a back seat.

Some supporters take on more of a leadership role, directing the group towards achieving their purpose. This is more apparent in the groups for people with learning difficulties, such as the Black People First Group. This group’s aims are to equip members with the means to speak up for themselves as well as to address issues around their identity as black people. The support worker organises activities with the consent of group members, such as cultural celebration days. Individuals are encouraged to think about their identities by, for example, putting pins on a map to indicate their countries of origin and those of family members.

A major concern is the degree of control that group members have over group activities, and how these activities meet their needs. This can be a particular issue, where emphasis is put on the supporters – sometimes by the young people themselves. However, while these issues of independence and dependency could potentially be a cause for concern, our sessions with the majority of the groups showed that such concerns were unfounded.

## Money matters

For some of the young people, money affects their ability to participate in their group’s activities. The African Caribbean Leisure Group is particularly dependent on members having money to pay for, or contribute towards, their activities, so cost is important to members:

“I like bowling. We used to go, but it’s a bit too expensive now.”

“... some of us might have bills to pay, so we’ve got to be careful of how much we spend.”

One young woman talked of her need to get out and meet people by coming to the group, but was not keen on meeting more often because it would cost too much.

Lack of money also affects the kind of activities that group supporters can organise. Those in the Black People First Group are restricted to in-house activities because they don’t have the funds to go on outside trips. Similarly, lack of resources probably affects the activities of the Self-Advocacy Group – another ‘housebound’ peer support group.

It seems that funding is a vital element of a group’s development and maintenance. Ideally, groups have enough funding for members to take part in activities with little contribution from themselves, and sufficient funding to expand the activities being offered by the group. This is the case for the Bradford Deaf group. But for some young people, such as those in the African Caribbean Leisure Group, group activities contribute to their sense of independence. Managing their own money, then, might be important to them in terms of maintaining independence.

## Transport considerations

The majority of young people cited travel as a factor that affects their group attendance. Three of the groups arrange transport for their members.

The Bradford Deaf group, for example, use a mini bus to collect the young women. For this group, reliable transport is important to parents, who are concerned about their daughters’ safety, and is more likely to persuade them to allow their daughters’ attendance of the group. The young women stressed the importance of this:

“First girls came by taxi, then ABDA [Association of Bradford Deaf Asians] got a mini bus and pick up everyone. Parents don’t like girls travelling alone [in] the

evening, as they can't hear if someone [is] following them behind. So [we] need to have mini bus to alleviate parents' concerns for safety."

This group has plans to get another mini bus in order to increase the membership and the number of outside activities they can undertake.

Those in the Coventry Deaf group do not appear to want transport for group sessions, but they would like arranged transport for any trips they might make, particularly if they are at night-time. As one woman said:

"If it was night-time, I'd probably get on the wrong bus or whatever, so I wouldn't be allowed to go.... It would be better if there was group transport because then my parents would let me go. "

While having transport provided by the groups is reassuring to some young people and their parents, others – such as those in the African Caribbean Leisure Group – resist organised transport because they feel it encourages dependency:

"It's like losing your independence, innit? If we're gonna go out and live, then we need to learn how to use the bus and all that."

This group went on to discuss how independence was important to them, and how organising their own transport to group sessions was part of being independent. Similar sentiments were not expressed in other groups, perhaps because of the African Caribbean Leisure Group's stated purpose of developing independence.

While having arranged transport has its advantages, particularly for those in the Deaf young women's groups, there may be a need for groups to explore the role that arranged transport plays with regard to their group aims.



# 5

## Summary and conclusions

It is clear that peer support groups play an important part in the lives of young black Deaf and disabled people. Attending the groups enables them to gain emotional support, make friends, and take part in a number of activities where they have fun or learn new things. The young people are also actively involved in running the groups and deciding how support is organised. Peer support groups for young Asian, Caribbean and African people specifically provide them with a comfortable environment to discuss

ethnicity and religious issues. They also enable them to talk about other things they consider important – disability, independence, Deaf culture and identity, for example. There are factors, however – such as having a place to meet, or money for activities – that affect a group’s organisation and development, as well as the kind of support it can offer. Nevertheless, all the young people seem to enjoy attending the peer support groups and are enthusiastic about the benefits they provide.

### Checklist for setting up a peer support group

If you want to start your own peer support group, here are some guidelines, as outlined by the young people we interviewed for this project:

1. Tell people you want to start a peer support group. This could be people in Deaf centres, disability day centres or social services departments. Talk to young black Deaf or disabled people, and find out what they think.
2. Go and visit another group to see what goes on and how it works.
3. Exchange ideas with other people to get an idea of what you want your group’s function to be – a place to meet other people, a place to learn things, or somewhere to have fun?
4. You may need to find somewhere to meet and some money to pay for activities or bus fares. Social services or black community groups may be able to help you with this.
5. Get volunteers or supporters to help out.
6. Tell parents about the group. If there is a support worker, they could visit to give information and reassurance to parents in the appropriate language.
7. Publicise your group. Decide what you want to say about it and how to communicate this. It could be a leaflet with words and symbols, which gives the name of the group, who will be running it, information about when and where to meet, contact numbers, and details about what will happen at group sessions.
  - Use word of mouth.
  - Advertise through black and minority ethnic radio and papers, or at community groups, churches, mosques and temples.

Get started!

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# Appendix A:

## Research methods

We initially identified and contacted 20 peer support groups throughout England. Of these, just 12 groups fitted our criteria – we wanted to talk to young people between 16 and 25 years of age who were actively involved in running their own group.

Of these 12, not all of the Deaf women's groups were approached, as they were well represented. Instead, we decided to give groups representing a range of impairments the opportunity to participate. We wrote to 10 groups formally to see if they wanted to work with *us*.

We eventually carried out two focus group sessions with each of five peer support groups: Black People First in Swindon, the Association of Bradford Deaf Asians Young Women's Group, the Coventry Asian Deaf Young Women's Group, the African Caribbean Leisure Group in Leeds and the Tower Hamlets Self-Advocacy Group.

All members of the Black People First Group attended both sessions, which took place at their own venue, a health centre. All members of the Association of Bradford Deaf Asians Women's Group also attended both sessions, with the support worker present as an interpreter. Sessions took place at their own venue, a youth centre. The first session with the Coventry Asian Deaf Young Women's Group took place during a trip to a National Deaf Children's Society exhibition. Three members were present, including one white woman as an observer. The second, attended by all members, took place at their new venue, a family centre. A sign-language interpreter was used in both sessions. Six members of the Tower Hamlets Self-Advocacy Group attended the first session, and all members attended the second. Both took place at their

school, and a support worker was available to interpret. All members of the African Caribbean Leisure Group attended the first session, which took place in a community centre. The last session, with four members present, took place in a refreshment venue.

# B

## Appendix B: Peer support group contact details

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Tile Hill North  
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Contact: Rita Mistry  
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Black People First Group  
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Health Hydro  
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Tower Hamlets Self-Advocacy Group  
Disability Advocacy Network  
40-50 Southern Grove  
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