# The views of young black disabled people on independent living

Independence is generally seen as a positive step for young people, leading to them becoming self-reliant and less dependent on others. Yet this may not be the same for young disabled people. This study is based on interviews with 44 young disabled people of Asian, African and Caribbean origin. It looks at their experience of independence and the influences on them leading active independent lives.

- The young black disabled people interviewed defined independence as having choice and control in their lives. However, family and cultural expectations sometimes determined how this choice was expressed.

- By being independent the young people felt they influenced what other people thought of them and what they could achieve as black disabled people.

- Whilst there was an association between independent living and living on your own, the young people felt how you lived your life and making decisions was as important as where you lived.

- The majority had negative experiences of primary and secondary education and how it had prepared them for adult life. Many young people felt that this was due to professionals' expectations of them being low because of their race, culture and disability.

- Many felt their education concentrated on physical rather than academic needs, so they did not achieve much. Those who did go on to further education had more positive experiences.

- The majority of these young black disabled people had specific goals they wanted to achieve and were actively working towards them. Some felt their growing sense of independence was a determining factor in achieving these goals.

- Few young people had contact with social care agencies, most relied on their family for care and support.

- Loneliness was an issue for most of these young people, particularly for those who were living alone.

- There was a lack of informal support with little chance for them to meet other young black disabled people and to share experiences.

## Background

Independent living has become an option for disabled people as a result of the 1990 NHS Community Care Act and direct payments (introduced in 1996).  Social care practice has focused on independent living, generally defined as a disabled person living alone with support.  However, whilst there has been growing interest in disabled people's experiences of independent living, few projects have examined what independent living means to black disabled people.

## What is independence?

The young people's definitions of independence focused on 'being able to do things yourself' and 'having rights'. Overall independence was about having choice and control in how you live your life.

> "Independence means having your own voice, you don't want anyone else to speak for you.  If you're capable of speaking for yourself you should do."

All those interviewed felt that independence was important.  They described how they were independent through achieving things.  Several gave the example of learning to drive.  Having to rely on family members for transport had restricted their activities; driving gave them the chance to go places at their own convenience. Others valued everyday life skills, such as making something to drink or being able to manage their own money.

Many demonstrated how independence could lead to a change in 'self-confidence and self-perception'. This often raised their own expectations of what they felt they could achieve.

A number of influences (both positive and negative) affected how these young people thought about and experienced independence. One of these was how others saw them and what they could do.

Family support, for example, could often restrict these young people's ability to be independent and achieve their ambitions because of the family's desire to 'protect' the disabled child.  But for others, family support encouraged the growth of their independence. Some people were given errands, to help them actively contribute to the household. For example, a physically disabled young Asian woman felt that her role in the family had changed as she had more responsibility in picking up and dropping off members of her family, now that she was able to drive.

For those who felt that they had achieved things, it was clear that what others thought of these achievements affected their own self-esteem and ideas of self-worth.

## Independent living

Independent living is often thought of as being able to live on your own.  However, whilst the majority of the young people agreed with this definition, they emphasised that being able to make your own decisions, develop skills and do things yourself were important elements of independence. Moving away from their family was not essential. One wheelchair user expressed it this way:

> "Some people may think, you know, well I'm not independent because I can't do it for myself. I can't go to town myself. I don't see independent living that way. I see independent living as I make the decision."

Most people emphasised the importance of 'making decisions' about how they lived their lives and having their 'own voice'. Although the majority of the young men and women were living with their families many felt that they were independent; to what degree depended on circumstance. For many of the young people living independently involved living with or near their families.

## Education

The young people had varied school experiences including attending special, mainstream and integrated schools. Whilst many welcomed the opportunities of work experience or learning independence skills which they had had at school, a significant majority were very critical of their school experience.

The majority had negative experiences of statutory education and felt ill prepared for adult life. Many felt they were treated differently because they were Asian, African or African-Caribbean. This was a particular issue for those who were the minority in mainly white schools. An Asian woman with learning difficulties stated:

> "... I think some of the teachers were a bit racist against me because I was the only brown one there. I felt a bit out of place, but it was all right after a while."

Schools did not appear to address the issue of identity and culture for many young black disabled people. Some people talked of how different

treatment by other young people and staff affected them. Significantly, their teachers' view of them influenced their own and others' expectations of what they were capable of achieving academically. Some young people mentioned how teachers saw them as 'lazy' or 'naughty'. Many suggested that these low expectations and negative perceptions affected how they were taught and their educational achievements, as well as their ambitions.

Some pointed out that the organisation of support systems within their schools did not help them to learn. One wheelchair user said that he needed individual support and the current class support system was limiting his ability to carry out his work. He explained that teachers saw him as 'lazy' or 'not trying hard enough' when in fact the support was slowing him down.

The young people suggested that their schools did not prepare them well for the future. Many felt their school catered for their physical but not their academic needs, resulting in their low educational achievement. A number had left school without any formal qualifications. Deaf young people in particular left school with a poor level of English. Some people did not wish to pursue further education, possibly because of their school experiences. But those who went on to further education described a more positive experience with better support systems; as a result both their educational achievements and future ambitions were raised.

## Ambition

The majority of these young black disabled people had goals and were actively working towards them. They had similar ambitions to their non-disabled peers: getting a job, going on to further education or getting married and settling down.

The younger men and women (aged 16-19 years) saw further education as the stepping stone towards a particular career. Many wanted to have professional careers such as working in engineering or teaching.

Others wanted to work, but felt that they were only suited to particular types of work, such as in the service industry. Whilst there were several reasons for this, their work experience was significant. Most had done factory work, packing, or warehouse placements, with the implication being that this was the only type of work suitable for them. The young people's own perception of themselves as a black disabled person and their value also influenced their expectations of employment. Many saw difficulties in getting employment because of their impairment.

Some also highlighted racial discrimination as a particular obstacle to gaining work. One African-Caribbean deaf man said:

> "… there are mostly white people and just having one black person, and deaf as well, is gonna make it really difficult I think."

Some young people wanted to become role models and felt that this was important to encourage young black disabled people in their personal development and independence. One said:

> "I want to be a famous Asian fashion designer for deaf Asian people."

Whilst all the young people had ideas about their future, some felt they could not fulfil their ambitions and their self-esteem was low.

## Support

All of the young people were known to social services departments and had had contact with social workers at some time during their lives. However, at the time of the study, very few were in contact with the social services department for their main care and support needs.

Many were not aware of what services were available or whether or not they had a social worker. There was a lack of information regarding social care practices and policies. For example, practically no young person had any knowledge of direct payments and how these could enable them to live independently.

Most relied on informal support in their everyday lives. Family were especially important for physical care needs and emotional support. Having family nearby was a particular issue for those who lived in their own accommodation.

Loneliness was an issue for most of these young black disabled men and women, and particularly for those who were living alone. Those who lived in their own accommodation wanted to share their experiences and socialise with others, but were not aware of any support groups to meet their needs. Existing disability groups in the four research areas either did not cater for young people or for the concerns of black disabled people. Most of the young people wanted the opportunity to meet other young black disabled people – those who shared the same race, food, and way of life – to learn about their culture, socialise and share experiences.

## Being a young black disabled person

Culture, ethnicity and religion were important to the majority of the young men and women, and influenced the extent to which the young people felt that they were independent.

The young people were very much aware of their ethnicity, but the most specific issues arose in regard to their cultural identity. Many spoke of being treated differently, although it was not always clear if they had been made to feel 'different' because of their ethnicity or because of their impairment.

Although some realised their experiences differed from those of white disabled people (some from their experience at school), others did not. Lack of opportunity to discuss race and culture as well as discrimination may be contributory factors here. In terms of disability, most understood they had an impairment. A number of people, however, deliberately hid their impairment. Others rejected the labelling of their impairment; for example, some people with learning difficulties preferred to describe themselves as having difficulty with reading and writing, rather than as having learning difficulties or being disabled.

Deaf Asian people expressed difficulties in understanding their culture and in reconciling family life with that of their English residential school life. Some spoke of difficulties that arose with their family because they did not understand the cultural practices and expectations of their family. They felt isolated with no common language with their family since their first language was either English or British Sign Language (BSL) while their family mainly used Asian spoken languages, and often did not use BSL at all.

Religion played an important part in the lives of these young black men and women. But some were denied the opportunity to participate in religious practices because of their impairment. Physical access and communication issues were the main obstacles.

## Conclusion

It is clear that a number of different things influenced the opportunity for young black disabled people to develop and express their independence. Several of the young people had some opportunity to fulfil achievements and to work towards their ambitions, but others spoke of meeting obstacles. Nevertheless, these young black disabled people felt that being independent was important to them, and a determining factor in achieving their goals for the future.

## About this study

This study is based on interviews with 44 young people of Asian, African and Caribbean origin. The work took place in four local authorities: one inner city authority in London, two county councils and a city council. The young people were aged between 16 and 30. The majority had a range of learning difficulties but others were deaf or hard of hearing, or had visual impairments, and some had multiple disabilities.

### How to get further information

The full report: **Between ambition and achievement: Young black disabled people's views and experiences of independence and independent living** by Tracey Bignall and Jabeer Butt, is published for the Foundation by The Policy Press (ISBN 1 86134 198 3, price £12.95).