

Between ambition and achievement

Young black disabled people's views and experiences of independence and independent living

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Introduction

In most societies and communities the rights and responsibilities of adults differ dramatically from those of children. The age which is seen to mark the transition from childhood to adulthood may vary from one community to another and one individual to another, but there is always an expectation that the transition will happen.

However, there is growing evidence that this change is effected by the experience of disability. If you have an impairment, not only might expectations of what you will achieve be different, but also the rights and responsibilities you can anticipate. The amount of support disabled people receive in taking on these rights and responsibilities may also be influenced by ethnicity, gender and family situation among other factors.

This study looks at how young black disabled people manage this change, and what independence and independent living means to them.

Existing research on black people and disability

The flow of research studies on black disabled people has steadily grown over the past decade. In particular there has been a growth in studies exploring their particular experience of social care services. Begum, for example, has investigated the experience of black disabled people living in Waltham Forest (Begum, 1992); more recently she has reviewed the implementation of care management and assessment (Begum, 1995). Shah (1995) has looked at children with disabilities in Asian families, while Caesar and her colleagues (1994)

have examined the experience of black service users in two Barnardo's-run projects for children.

There have been other more wide-ranging studies: Baxter et al (1990) carried out a survey of services provided by social care agencies in areas where the black population constituted more than 4.5% of the local population; GLAD (the Greater London Association for Disabled People) carried out a study of disability and 'ethnic minority communities' in three London boroughs, and paid some attention to the role of voluntary groups (GLAD, 1987).

In summarising the evidence from these and other studies Butt and Mirza (1996) noted:

The fact that major surveys of the experience of disability persist in hardly mentioning the experience of black disabled people should not deter us from appreciating the messages that emerge from existing work. Racism, sexism and disablism intermingle to amplify the need for supportive social care. However these same factors sometimes mean that black disabled people and their carers get a less than adequate service. (Butt and Mirza, 1996, p 94)

Importantly, a number of the studies suggested that this disheartening experience for black disabled people is sometimes alleviated by voluntary or community organisations attempting to fill the gap left by the failings of existing service provision (GLAD, 1987). Baxter et al detailed some of the voluntary organisations working with black disabled people to open up employment opportunities (Baxter et al, 1990). The ADAPT survey of service providers and

Asian families with at least one disabled member concluded:

Some voluntary agencies have been able to attract more Asian service users. One reason may be that voluntary groups are able to be more flexible in their approach to working with people/ children/families from varying backgrounds. (ADAPT, 1993, p 11)

This growth in research on black disabled people has recently been accompanied by more regular attention to black disabled people in 'mainstream' research. In her review of the impact of the Independent Living Fund (ILF), Lakey (1994) noted that some of the 1,043 disabled people covered by her postal survey and the 300 disabled people interviewed for the study were black. Layzell and Lamb (1994) also made reference to black people in their investigation of community care reforms and their impact on the lives of disabled people. Morris (1993a, 1993b) ensured not only that black people were represented in her study of community care and independent living, but that their experiences were presented and analysed.

Any attempt to characterise this disparate group of studies should be treated with caution. However, there has been a clear move away from the *medical* model of disability (defining disability in terms of impairment) to the *social* model of disability (defining disability in terms of social factors which create barriers and deny opportunities; Morris, 1995), accompanied by increased attention paid to people with learning disabilities. Importantly, the research specifically on black disabled people has also changed from attempting to find pathological explanations for higher incidence or prevalence rates of disability, to understanding how care is presently organised and how this is contributing to the lives of black disabled people (Ahmad, 1996). Additionally, some of the conceptual frameworks that have been used to understand and analyse the experience of discrimination (racism, sexism and disablism) have begun to develop in more complex ways, with the concept of multiple oppression being used, rather than double or triple discrimination (Begum, 1994).

However, gaps in our knowledge persist – in particular there is little information about young black disabled people and their experience of

independent living (as well as any support or services provided by the communities themselves). This is in part due to a general lack of information about young disabled people and independent living. Morris noted in her review of disabled children living away from their families that, while there had been a growth in interest (and research), "the current focus on the need to support young people who are leaving care completely ignores disabled young people" (1995, p 80).

To this we could add that the research has further ignored young black disabled people. For example, while Biehal and her colleagues (1995), in their recent investigation of the experience of those leaving care schemes, devoted some time to looking at young black people, they did not indicate if any of them were disabled. Interestingly, they did note the positive response of these young black people to the black-run hostel which some used before moving on to permanent accommodation.

A further explanation of the gaps in existing research is the weakness of research on disability. For example, in her review of the impact of the ILF, Lakey (1994) used 'ethnic minority' disabled respondents. She noted that her survey showed "only 26% of respondents from ethnic minorities said that they were getting sufficient help, compared with 43% of white respondents" (1994, p 26). She went on to say, however, that the number of black respondents was so small that the information gathered was not sufficient for statistical presentation, and the qualitative data collected was not presented in the report (Lakey, 1994).

Others appear to have chosen not to exploit their data. For example, Layzell and Lamb's (1994) survey of being disabled in Britain included black people in the sample but referred to them specifically in only one of the three reports based on this survey. Sainsbury et al's (1995) evaluation of the Disability Living Allowance and Attendance Allowance also has black people in the sample, but again fails to refer to their experience specifically. In her study of community care and independent living, Morris (1993a, 1993b) provided a more detailed picture with regard to black disabled people. However, the survey drew on people from 19 to 55 years of age from a range of ethnic backgrounds, and therefore was not able to

reflect on whether the experiences identified are true of *young* black disabled people.

Additionally, as Morris (1995) has reminded us recently, there is still much to be done to allow disabled children's subjective experiences to be heard.

Equally, we must add that some major studies of black and minority ethnic communities have paid scant attention to disability. For example, while Modood et al (1997) highlighted the comprehensive nature of their work, presenting data on ill-health in particular, they referred to disability only in the context of its impact on economic inactivity. There was no discussion of how disability influences identity, even though much of the book attempted to develop new ways of describing black and minority ethnic communities.

A final note is that anecdotal evidence appears to suggest that there is a difference in both what black communities identify as independent living and how it is regarded within black communities. On the latter point Baxter et al's (1990) report presented the outcome of a training exercise which asked 30 Afro-Caribbean, Asian and white people to rate on a scale of 1 (positive) to 5 (negative) the importance of issues such as independent living. The 10 Afro-Caribbean respondents all rated independent living as '1' (positive), while five of the Asian respondents rated independent living as '3' and a further five rated it as '5' (negative). While this evidence is limited, it does suggest that this report will also need to consider the differing concepts of 'independent living' for young black disabled people, and the importance attached to achieving it.

Our aims in this research

The aims of this research were to:

- investigate young black disabled people's experience of independent living;
- investigate young black disabled people's views on the concept of independent living;
- inform social care agencies working with young black disabled people to develop better practice;
- consider more effective strategies for building community support for young black disabled people.

Why this research is important

Our starting point for examining the experiences of independent living for young black disabled people must be the voices of these young people themselves. Roy Thompson (1994), from *Jawaan aur Azaad* – a group of black young disabled people – notes:

“As you can see, I am disabled. What you cannot see unfortunately is that for the past six years I have lived in this community as an independent person, doing as my disability permits, everything any so-called normal person would do or want to do”. (Thompson, 1994)

Accounts suggest that there is a real need for many young black disabled people to attain independent living. Angela Smith, recounting her childhood and youth, recalls:

The relationship with my mother became increasingly strained. It felt as though she had given up on me. I became increasingly introverted and depressed. My brothers and sisters were all busy with their schooling and generally growing up. During the eight years I had been away, my family had become accustomed to not having me around for long periods. They were no longer use[d] to thinking in terms of accommodating my needs. I suppose life was more flexible and adaptable. My unexpected return home had cramped everyone's style. (Smith, 1994, p 134)

Advocates for the improvement of black disabled people's experience of social care have advocated equally strongly making independent living an option for black as well as white disabled people (Begum, 1992).

The emerging interest in independent living in black communities has been paralleled by developments in governmental policy. The government has outlined its aims for the provision of community care services to enable people to live as 'normal' a life as possible in their own homes or in a homely environment in the local community (Secretaries of State, 1989). Elsewhere, they emphasise choice and independence. At the same time, the 1989

Children Act imposes specific duties on social services departments to provide services to disabled children, as well as imposing a general duty to promote the welfare of those defined as 'children in need'. Begum (1991) highlights the possibilities that this suggests for a radical improvement in the experience of black disabled children. More recently, the 1996 Direct Payments Act allows local authorities to make arrangements to provide disabled adults (under 65 years old) with money rather than services, so that they can make arrangements themselves to meet their care needs in the community.

It is difficult, however, to assess from the evidence of existing research studies whether these legislative changes have had the desired effect for young black disabled people, with some black-led user organisations suggesting black disabled people do not receive the information they need to benefit from these changes (Butt and Box, 1997).

A consistent argument of those advocating independent living is that it enables disabled people to exercise choice and control. The original ILF made a source of financial support available for this purpose. Kestenbaum notes that:

The ILF supported a concept of independent living, which is about more than merely being able to live in the community. More important, it is about the ability to exercise choice and control in ways that most people without disabilities take for granted. (Kestenbaum, 1995, p 5)

The shift in responsibilities (and resources) that accompanied the 1990 NHS and Community Care Act saw the end of the original ILF and the establishment of two new funds: the Independent Living (1993) Fund and the Independent Living (Extension) Fund, as well as the Independent Living Transfer given to local authorities to reflect their new responsibility to disabled people.

The opportunities offered by this source of funding have been recognised as invaluable, yet, beyond Lakey's (1994) suggestion that black people appear to be less satisfied than white people with the allocation of resources, there is

limited evidence on the effect of independent living funds on the lives of black people.

However, there is existing evidence that there are families with disabled children who are particularly vulnerable and demonstrate high levels of unmet need: among these are black families (Beresford, 1995). Other evidence also suggests that poverty is more widespread among black families (Hills, 1998), particularly among Pakistani and Bangladeshi families (Berthoud, 1997). This creates a scenario where young black disabled people approach independent living with a history of unmet need and the consequent increased need for proper financial support to make independent living viable.

The young people in this study

The study is based on interviews held with 44 young disabled people of Asian, African and African-Caribbean origin. These young men and women had a range of impairments: some had learning difficulties, others were deaf or hard of hearing, or had visual impairments. Some of these young people had multiple impairments. All had a variety of communication needs. The Appendix gives more details on the young people and their backgrounds.

The report

There are six chapters of findings from the interviews and profiles of four of the young people that we interviewed. Chapter 2 discusses the young people's ideas of independence and independent living. Chapter 3 examines how these concepts are linked to their views about themselves. Chapter 4 develops this further by looking at their ambitions. The experience of education plays a part in how independence is viewed and achieved, and Chapter 5 looks at this topic. Chapter 6 examines the young people's experience of work. In Chapter 7 we look at their contact with social services departments. The conclusion, Chapter 8, draws together the findings from the different chapters, as well as highlighting some of the implications for policy and practice.

What is independence?

As part of the ‘growing up’ process for young people there is a recognition of the gradual change from the dependence on others, to independence and self-reliance. Gaining independence is seen by many as an important step in the transition to adulthood. Yet this process varies according to the young person and their expectations of themselves, as well as how they are perceived by adults, especially parents.

This chapter examines how the 44 young black disabled people in this study define and experience independence, what influences their views and how important independence is to them.

Definitions of independence

For most young people, increasing independence is both an objective fact and a social construct: they become physically and intellectually able to do more for themselves and the attitudes of those around them change because they are growing older.

This dual aspect of independence is particularly relevant for young disabled people. For proponents of the social model of disability the movement of a young disabled person towards independence is hampered as often by the attitudes of others as by any physical or intellectual impairment. Definitions of independence, therefore, will tend to move between two models: one concerned largely with doing things for oneself and another with social expectations, permissions and prohibitions.

The young people in this study saw both models, implicitly, as important. The term ‘independence’ produced a variety of responses from the young people in this study. The main descriptions focused on doing things yourself, having rights, making choices, freedom of expression and how you live. Some definitions of the word ‘independence’ were:

“Um ... being independent is like, doing things for your own self. No, being able to do what you want to. Shouldn’t think ... I can’t do it. Should always give it a try.” (Rifat, a 20-year-old woman with physical impairments)

“Independence means freedom to do things that I want to without the aid of and having to rely on others. Going where I want and doing what I want, any time I want.” (Imtiaaz, a 19-year-old Asian man with physical impairments)

“Independence means how you cope in life and how you live on your own.” (Elaine, a 20-year-old African–Caribbean woman with learning difficulties)

Doing things unaided

Many of their definitions of independence related to their own experiences, particularly in terms of what they felt they had achieved or wanted to achieve. Independence for many of them was about doing everyday things without the assistance of others, such as making their own meals, making the bed, getting dressed, and helping out in the home.

Escaping from being dependent on others was

central to this notion of independence. Many described independence through examples of what they had done and the effect this had had on their lives. For them, unless they could 'do' something, they did not see themselves as being independent. Being able to overcome challenges proved, both to others and to themselves, that they could cope. Rifat, who was in the Sixth Form (Year 12/13) at school, explained that she gave up her classroom assistant because she felt she could cope and wanted to be independent.

Travel

Most of these young people were reliant on family members or access to appropriate transport to get around. To them, being able to travel by themselves seemed a significant achievement:

"But mostly I – one of the things which I did quite a lot on the bus – you know, I visit my uncle and grandma and cousins. They live in Luton.... And I used to get the 311 bus there, the 311 bus, and then, that one thing that I do, I do independently." (Nikhil, a 26-year-old Asian man with learning difficulties)

Several had gained considerable confidence from being able to travel independently. Sohail, an 18-year-old visually impaired Asian man, felt at his most independent and confident when travelling:

"I wasn't confident talking to public [sic] when I was young, about 11, 10. At 15 had confident and I asked public cross me road over – any public." (Sohail)

Some of the young people had travelled abroad and this has had an impact on their lives. One young woman, who along with a group of friends had made all her own arrangements for a trip to America, had been so impressed by the disability awareness and facilities for disabled people there that she wanted to live there eventually.

Driving

Several described being able to drive as empowering, and said it gave them a sense of independence. Imtiaaz explained why he had wanted to drive:

"Because I wanted to go places, I wanted to do things.... Before, I had to wait and see when [it was] convenient for the people and [it was] not always convenient for me, so I wanted to so I didn't have to rely on others...." (Imtiaaz)

Driving not only enabled them to travel and increased their self-reliance, but for some it also gave them a more significant role within their family. Tubassam, a 24-year-old Asian woman with physical impairments, said:

"They laugh, I'm their driver, I drive them around wherever they want to go – shopping, or Tesco's or whatever, yeah. My mum's just gone abroad now and I went to drop her off at the airport, so yeah." (Tubassam)

Those who drove mentioned how this enriched their lives, but others, while acknowledging the



change being able to drive could make to them, felt that it was beyond them. Fear was a factor for one young woman, while one young man felt he would not cope with having to know all the road signs.

Choice and control

Exercising control over various aspects of life was a vital component of independence for many of these young black disabled people. They expressed their ideas of independence in terms of exercising rights and making choices. What mattered, it seemed, was having the opportunity to be involved in decision making. This was important in itself, whether or not the decision made reflected their choices, simply being involved in the process gave them a sense of inclusion and of being valued.

The importance of control and involvement was well expressed in the following comments by two young Asian women:

“Independence means to have your own voice, you don’t want anyone else [to] speak for you. If you’re capable of speaking for yourself you should do.” (Tubassam)

“For me, independence means living my own life – not being with my parents, being by myself so I can do what I want, control my own life, control my food, my cooking, go out. I mean that, that’s what I think independence means.” (Fatima, a 20-year-old deaf Asian woman)

For some, particularly those at school, lack of choice was a serious issue. They felt they had not been consulted about the type of school they were to attend, and for one young man his lack of choice was a particular problem in his work experience placement. While non-disabled young people may express similar dissatisfaction, an issue for young black disabled people is how others perceive the effect which their disability has on them as an individual.

The problem is the general perception of what young disabled people can cope with and what responsibility they can be given. Limited involvement in decision making is something most young disabled people endure; even with current changing dynamics of familial relationships, parents still remain in control of the situation, whatever the age of the disabled person (Walmsley, 1996).

Several of the young people reported that they were able to participate in decision making within the family – for example, about going on holiday or to college – but the extent of such involvement varied according to individual family circumstances and situations.

Money

Income has often been used as a measurement of independence (Biehal et al, 1992; Flynn and Hirst, 1992; Doyle et al, 1994). There was considerable variation among the young people in this study in terms of who had money of their own and which of them could actually access it themselves. Most received Disability Living

Allowance and some other benefits. Others were given money by their parents, usually for specific purposes such as attending day centres or college, rather than on a regular basis.

A number had been taught by their families how to manage their money, or learned to do so through independence skills training. They were able to use their money as they wanted, often with some support, such as going shopping with relatives. A few had their own bank accounts and could therefore access money themselves. One of the young men saw himself as independent because he paid his mobile phone bills with his own money.

For some, access to money was more difficult. In particular, Jasbir, a 17-year-old Asian deaf man, expressed extreme anger at not being able to get any money when he was home from residential college. Jasbir questioned his right of access to his Disability Living Allowance which was banked by his parents. Seema, aged 26, had a physical impairment and currently attended a day centre: she explained that she had difficulty in gaining access to her money because her mother thought that her impairment made her incapable of managing money. When she could gain access to her money, it gave her independence to buy things for herself, rather than having to ask her mother.

Most of the young people interviewed saw access to money as an important element of independence. Even those who did not currently need such access, saw it as an important part of an independent future, particularly if that future was to include getting work and having a family.

Forming ideas about independence

Generally, a combination of factors influenced these young people’s ideas about independence. Talking to friends, information obtained through school, or involvement in disability groups had all helped to form their ideas.

Their families strongly influenced their views, particularly in relation to where and how they might live independently. Some talked of their families encouraging them to be independent. One Asian man described his father telling him to try and do things for himself: Mumtaz’s

impairment meant that he could not walk very far or very fast, and his father had suggested that he should try to walk a little more each day, to improve his stamina and skills, and “to be more independent”.

Many of the young people interviewed had formed their ideas about independence in the absence of accurate information or training in relevant skills. A small number had been taught skills, such as shopping and cooking, at school or training centres. Although such schemes existed, very few of the young people were aware of them.

An even smaller number knew of the Direct Payments legislation and the impact this might have on how their needs were met through their local social services departments. It may be that in some of the four research areas the schemes were in the early stages of implementation and the young people would therefore have had limited access to the schemes. But this does not explain why even those living in the areas where such schemes were being implemented lacked information about the Act. Whether or not they were typical of young disabled people in their ignorance of these entitlements, it should be a cause for concern that so few of them had any knowledge of this important legislation. Also, only two of the young people were aware of the local authority housing process and what they needed to do to obtain accommodation.

A probable consequence of this lack of knowledge is that it effects young black disabled people’s thoughts about independence. It is not possible to make informed choices about living independently without knowing what might be available in terms of support, equipment or services.

In many ways, the definition of independence for these young black disabled people was no different from that of their white counterparts (Bennion, 1988; Flynn and Hirst, 1992). However, it is the expression of independence and its effect on their lives in relation to race, culture and religion which is of significant interest, and these will be considered in the following chapters.

The importance of independence

The value given to independence varied among the young people. Most saw independence as having the potential to affect their lives profoundly, leading to major changes and enabling them to achieve their aspirations.

Some saw it as leading to their taking responsibility for all the main aspects of their lives. For them, such responsibility would cover current activities such as whether they went to a day centre or college and what else they might choose to do in the daytime. For many others, however, becoming independent suggested critical changes in their lives and their relationship with their families.

Fauzia is a 25-year-old woman with physical impairments, whose growing independence has led to a changing role within her family, with her taking on more responsibility, particularly in driving her family around and undertaking day-to-day tasks. She saw that this had already changed their views on what she was capable of achieving. It had also changed their expectations of her, with marriage now being seen as a real possibility.

Another young physically disabled woman, Pinky, explained the importance of her mother allowing her to be more independent:

“She, she leaves me on my own, now I have a ... I have a bit of time to myself.”
(Pinky, a 22-year-old Asian woman wheelchair user)

It was important for Pinky and her mother to have a break from each other’s company. For this young woman increased independence had given her more control over her own life.

For some, however, the two-sided nature of independence also implied risk. The question for them was whether independence would bring them more control over their lives, or whether it would open up new areas that they might find difficult to deal with because they lacked relevant experience. A number expressed doubts as to the extent of the independence they would be capable of handling. Even though they felt independence was attainable, moving into an unfamiliar situation would be difficult for them and, in some ways, frightening.

Rajesh, a 17-year-old wheelchair user, mentioned the difficulty in making good choices:

“It’s hard. You don’t know which way you have to go do you? You just make the choice that you think is right. So I see what happens.” (Rajesh)

Leaving home

For many of the young black disabled people independence and independent living were interchangeable terms, producing interesting but contradictory ideas. Most of the young people in this study were currently living at home with their family, but they clearly associated independent living with moving out of the family home:

“Go and live by yourself, yeah, yeah.”
(Pervez, a 25-year-old Asian man with learning difficulties)

“Living on my own.” (Pinky)

For most young people in Britain, setting up home, by moving out of the family home to a ‘place of your own’, is an acknowledged part of the growing-up process and the move towards independence. The young people in this study had similar perceptions and aspirations: for them it seemed inevitable that people live by themselves as adults. According to Tariq, a 16-year-old man with moderate learning difficulties, currently living with his family:

“I would like to stay with my mum, but you can’t do that when you get older can you? You’ve got to live on your own.” (Tariq)



A number were definite about wanting to move out of the family home, whether to live with a girlfriend or boyfriend, with support, or on their own. Anwar, a 25-year-old man with severe learning difficulties, firmly

expressed his desire from a number of options: “Yeah, I live on my own”. Elaine had even approached us before her interview asking for information on how she could find a place for herself, as she definitely wanted to live on her own.

Perceived advantages of leaving the family home

Deciding how they wanted to live was a very individual matter for these young people, varying according to their individual circumstances and their relationship with their family. Some saw living on their own as a means of getting out of a difficult situation at home: some had disclosed abuse, for example, and saw leaving the family as a way of alleviating their situation. In the main, however, the young people identified more positive aspects of living away from the family home.

Alfred, a 17-year-old African man with learning difficulties, currently living with his mother and sisters, talked of getting a place with his girlfriend. In the discussion of what it would be like to live on his own, away from his family, he explained why it would be good to have his own place:

“Yes, by myself, not to boss, people bossing me about. Just to get up and clean the house, have my own house by myself. No no, my house with my girlfriend. And that would be good.”
(Alfred)

Living alone was seen by some as a step towards achieving full independence. Hosni, a 29-year-old woman with learning difficulties, expressed very clearly why independent living for her meant living away from her family:

“You have to learn to live on your own sometime because you got to learn how to do things by yourself. You can’t rely on your parents the rest of your life. You can’t live with your parents for life can you?” (Hosni)

A number had experienced, or were currently experiencing, living away from home. Some had gone away to college or university while others had attended independent living schemes. Nitin, a 24-year-old man with learning difficulties,

explained what it was like for him at his independent living scheme:

“I used to live ... I went to [an independent living training centre]. I’m not living [with] mum and dad now, I used to, now I’m going away. When I went to the [independent living training centre] my mum and dad they, they, can give me, I can do my own, make my own tea and do my own lunch, make my own bed.” (Nitin)

Perceived challenges of leaving the family home

Most had a clear idea of the changes and challenges that leaving the family home would entail. These were associated with having to do more for themselves, and taking on responsibility for all the aspects of daily living which others had previously addressed on their behalf. They were also aware that they might need help or specialised equipment to achieve this.

Jane, a 24-year-old African–Caribbean woman with learning difficulties, spoke of such changes:

“Well, when you move into a place of your own you have to do everything for yourself and take on a lot of responsibility, and you have to like, sometimes it gets lonely but you can like invite friends round, but you have to take that responsibility.” (Jane)

Also, Elaine, had had discussions with her mother about living alone, and recognised the need to make her own decisions, and the difficulties this would probably entail:

“It would be hard because you have to go to work, you have to cook for yourself, you have to pay the bills, invite people over, that’s it.” (Elaine)

Others suggested the possibility of loneliness if they were to live alone. Javed, a young man living in his own home, talked of how this had affected him:

“Well I do like it, but it’s very difficult because through my diabetes, which is really bad, I need attention from my

mother, and it does get lonely and boring on your own.” (Javed)

Living with friends or getting a flatmate was mentioned as a solution to this. Paul, an 18-year-old deaf African–Caribbean man, told us that he wanted to move out of his family home but could not see himself as living alone:

“Well, because I think I’d like, you know, I’d need to have friends, you know, I don’t actually want to be on me own.” (Paul)

Of the young people living with their families who expressed a wish to live on their own now or sometime in the future, having family support nearby was a significant factor in deciding where they wanted to live. Most wanted to be close to their family home, which is understandable given that, for the majority, their family is their main source of support and is likely to continue to be in the foreseeable future.

Many of the perceived problems could be solved by support that is currently available. However, many of the young people in the study were not aware of any options for support other than through their families.

Meeting the challenges

The everyday experience of those already living away from their families was somewhat different from the vision of the other young people wanting to do so.

Four described themselves as living independently. Jasvinder, a 25-year-old Asian deaf woman, was living in a house with a younger sister; Abdul, a 25-year-old man with a physical impairment, was married and living with his wife and children; Javed had multiple impairments and was living alone; and Azhar, a 22-year-old with learning difficulties, lived in a semi-independent home with two other people and 24-hour support.

These four explained how they took responsibility for themselves, and managed their own daily living. The positive elements they identified were: getting away from noise in the family home; being able to play their own music when they wanted to; and making their own decisions. Even so, they raised questions about

the difficulties of obtaining adequate support and dealing with loneliness.

Living independently within the family home

For others, however, living alone was not the main issue: what was important to them was the ability to manage their lives independently. For Zafar, a 22-year-old man with physical impairments, living by himself was not the essence of independent living:

“I would think independent living is not necessarily about being able to do things yourself physically, doing things yourself, but it’s about making the decision yourself. Making a decision yourself.... 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.” (Zafar)

Although the majority associated independent living with living on their own, some felt that this was not an achievable or desirable option. Thirteen of the 44 young people described independent living as something they were either doing – or could do – while remaining within the family home. They felt that living on their own would not be an option, given the advantages of remaining with their families.

For example, Riaz, a 17-year-old visually impaired man, has two older brothers. Both were visually impaired and both had moved out of the family home. Riaz felt that there were disadvantages to moving out of the family home:

“I think if you live independently it’s got to be for the right reasons, like you got married or something. I think it’s a waste of money and time if you live on your own for now’t when you can stay at home, and everything is paid, done for you. All you’re doing really, you’re just wasting money for nothing.” (Riaz)

He also felt that he was living independently, while at home with his family:

“I do everything for myself, and that means like, I make all my decisions. I’ve never been stopped doing anything I

want to do. And basically if you live on your own, you’re doing all them things anyway. The only difference is paying out money when if you lived at home you wouldn’t have to – pay out for.” (Riaz)

Riaz contributed to some household bills.

For some of the young people, the effect on their relationship with their families if they were to move away from home was an important consideration. For Bina, living by herself was not an option, “cos my mum wouldn’t like it”. Several others implied similarly that this would not be acceptable to their families.

Others felt they needed to remain at home, not merely in order to keep family support, but because they were not sure they would be able to cope alone. In particular, those who were deaf or hard of hearing talked of the difficulty of communicating both outside and within the family. The problem was more about spoken languages other than English than about British Sign Language (BSL). Although deaf and hard of hearing young people may use BSL and/or expect English as their spoken and written language for lip reading and literacy, Asian deaf young people have an additional language barrier within their own communities. These young people used BSL or lip-read English while parents often spoke Urdu, Punjabi or Bengali rather than speaking English or using BSL.

The age factor

There are some areas of disparity between those aged 16-19 years and those over 20 years old. Those in the younger age group (with the exception of two young people actively seeking to leave home) were happy being at home with their families. Although some of these young people talked about living on their own, their more limited life experiences left them currently ill-equipped to find a home or get a job.

Gender

It has been shown that the move towards independence for women is more limited than for men (Flynn and Hirst, 1992; Blackorby and Wagner, 1996). Indeed both the men and women in this study (young Asian women in particular) acknowledged that women had more

limited expectations and opportunities than men, such as whether or not they could go on to college. Nevertheless, this varied from family to family.

Summary

Independence was seen as important for the majority of these young black disabled people. They saw it in terms of being self-reliant and expressing their independence in practical ways such as travelling, driving and spending their own money. Access to money was a particular issue for many of these young people. They also saw independence in terms of being able to do things their own way and making choices.

A number of factors influenced the terms in which they described independence. Families had particular influence in encouraging some young people to do things to cope with their impairment, and also enabling them to be independent. Most had little information to help them attain independence, although some had been taught independence skills at school or day centres.

The majority associated independent living with living on their own. Living alone was seen as inevitable at some stage in their lives. Many had clear expectations of what living on their own would entail, specifically that they would be able to make their own decisions and do what they wanted. However, for those who were already living independently, the practicalities were somewhat different. Loneliness and the need for practical support were particular issues for them. While many of the young people talked about living on their own, in the main they appeared happy with their current living situation although the extent to which they felt they were able to express their independence varied.

Profile: Paul

Paul is an 18-year-old African-Caribbean deaf man and the eldest of three children. His family are from Dominica but he was born and brought up in England. He lives with his mother who is supportive, not only to him, but to his other deaf friends, finding out information and helping them to fill in forms for benefits such as Disability Living Allowance. He is currently in his first year at college doing a GNVQ Intermediate Art course.

He regularly goes to a club for deaf people, which he has been involved with since the age of five. He feels that this club is the only place for him and his other deaf friends to meet. It caters for all ages of deaf people, with the majority being in their 30s. He attended a school for the deaf for most of his education, but also had experience of mainstream schooling. Of his mainstream school he said:

"I was very, very nervous because most of the children there were gonna be hearing, but I did make some new friends there and I ended up having a good time. Some of them understood a little bit of signing because I used to, you know, teach them."

However, the teaching was a mixture of sign and spoken and written language, with more emphasis on oralism. Oralism created some difficulty since, if sign language was not available, the pupils had to communicate with the teacher via notes. Paul left school with very poor English.

However, he does not want his children to go through the experiences he had in a special school:

"What I want for my children is that they go to school on a day basis and not boarding, you know, so that we can love them. I'm not ... I don't think they'll learn anything in deaf school, I'd want them to go to hearing school."

At school Paul enjoyed particular sports and played for the school in the local football league. He is still involved in football and has ambitions of being a football manager or coach.

Paul regularly contributes to the household bills and assists with household chores. He sees learning to manage money as an example of his independence and feels that this is important because:

"I've got to be responsive [sic] in the future, if I have a family and children, you know, and I will still have to have bills to pay, so you know, I need to learn it for responsibility."

He talked a lot about going to university and was looking forward to the changes and opportunities this would bring. He intended to do drama or a photography course and was clear as to what the university should be like:

"I don't want to go to a university where there's just a few deaf people. I want to go where there's lots of deaf people, so that there's a social life as well, I mean, there's a lot of deaf people at [...] University, so that we can help each other and meet after as well."

Paul has worked in summer jobs but could foresee difficulties in getting a job because of his deafness:

"It's difficult to get jobs. I now get DLA benefit because I'm deaf, so it's gonna be, you know, it's almost impossible to get a job. It's difficult meeting hearing people 'cos you know, I haven't got any speech, or good speech."

As well as going to university, his future plans include leaving home at some stage to live with friends, who are an important part of his current support systems. He regularly meets with friends and talks about his plans:

"I mean my life's improving at the moment because, you know, I like to go out with deaf friends at night and we can have a chat and we travel round. We're all going as a group, we're arranging a trip to Spain next year and before the year 2000, I'd like to go to Dominica to see my family."

3

Who am I?

The extent to which these young people saw themselves as independent was linked to their self-image and experiences: what they thought about themselves influenced what they thought they could do. Several themes emerged as having shaped their sense of their own identity: understanding their impairment and how it affected them; the perceptions of others; the influence of role models; their understanding of race, culture, religion and community; and the impact of gender.

Understanding disability and impairment

The ways in which the respondents made sense of their impairment varied considerably. The majority described their impairment and its effect on their lives by explaining the nature of their impairment and its cause. For example:

“I, as I said, I was born in Pakistan and when I was walking about and, you know, I suddenly got a temperature. I fell asleep, woke up, believe it or not couldn’t walk. It was just a sudden thing, polio I had, it was called polio, and that’s how I caught ... that’s why I’m in a wheelchair.” (Tubassam)

“Got learning difficult.” (Anwar)

“They discovered that I had Friedreich’s ataxia – my disability – and it was getting ... it was getting worse, and so I was falling over a lot and so they decided to put me in physically disabled school, in Essex.” (Pinky)

Others did not use medical terminology for their impairment in such detail, but clearly understood its nature. They explained their impairment by describing what was difficult for them:

“Well I couldn’t write that properly, no, and I weren’t that good with maths at the time.” (Dillip, a 16-year-old Asian man with learning difficulties)

“I would say I need more help with work, that’s all.” (Kwame, an 18-year-old African man with moderate learning difficulties)

The majority of these young disabled people were able to describe their impairment, and express an acceptance of being disabled. For some this was not the case – several did not accept the label of ‘a disabled person’. One young man in particular did not accept being labelled as someone with learning difficulties, and therefore disabled; he said:

“Don’t know. I don’t think, I don’t think it is a disability so...”

describing himself instead as:

“... just not that bright that’s all.” (Kwame)

Those young people who were deaf or hard of hearing similarly rejected a disability label. They saw a communication barrier or difference of language but did not see this as disabling. Indeed, many were leading active independent lives, going to university and travelling abroad. One woman was living on her own.

There was also a group who understood neither the term disabled nor the nature of their impairment. Pervez, a young man with learning difficulties, knew there was something different about him but did not understand what it was. He asked questions about this difference several times during the interview:

- Pervez: "Is there something wrong with me?"
- Interviewer: "Something wrong with you?"
- Pervez: "Yeah."
- Interviewer: "What's wrong with you?"
- Pervez: "Is there something wrong with me?"
- Interviewer: "I don't think so."
- Pervez: "Is there something wrong with me?"
- Interviewer: "No."
- Pervez: "Is there a problem wrong with me?"
- Interviewer: "No."
- Pervez: "How do you know that? I thought there was a problem wrong with me, learning difficulties or..."

His father had told him that there was something wrong with him, that he had "a problem of learning difficulty", but Pervez did not know what this meant.

These young people felt that having impairments and being disabled had affected their lives in a number of ways. Some saw their specific impairment as having restricted them in terms of independence. Others spoke of a lack of educational achievement and opportunity, lack of access to money and isolation within their own black communities.

Many, however, had come to an understanding about their impairment and did not feel restricted but were able to be independent. Some young people talked of overcoming challenges, and being able to do what other non-disabled people did, such as travel, or go to university.

The perceptions of others

The disparity between what young people feel about themselves and how others describe them is important.

First, a young person's self-image will probably influence any expectations they have of themselves. It has been shown that young disabled people, and young people with learning difficulties in particular, often have lower self-esteem than their non-disabled counterparts (Flynn and Hirst, 1992) and that being labelled 'mentally handicapped' impacts negatively on young adults' self-perception (Flynn, 1989).

Second, how others perceive them can influence young disabled people's own perceptions of their impairment, and their self-worth. This may, however, depend on who is reinforcing the image of the disabled person and how important they are to that disabled person.

Two young Asian deaf women were very aware of the ways others perceived them. One, Saira, was doing a course at college and planned to go away to university in order to work for a design degree:

"When I was young, people thought I was thick. When I started school they realised that I was deaf. I just couldn't hear. Sometimes my mother objected to me because I was deaf and would have preferred me to be hearing. People thought I was thick but I was just deaf. I'm happy, I'm very happy now – I'm just like a hearing person, I'm the same, we're equal. The only one small thing about me is that I cannot hear, that's the only difference." (Saira)

The other, Fatima, who worked part time for an Asian Deaf Women's group, talked about the lack of expectation others had of her:



“If I meet somebody and they find out I’m deaf, they don’t believe that I can help them and they’ll go away again and they just withdraw – they won’t ask me anything.” (Fatima)

Both these young women had a clear understanding of themselves and their deafness which did not prevent them leading independent lives.

Reconciling their self-image with how others see them is essential for young black disabled people in building up a sense of their own identity. Several of the young people described being labelled as inadequate, and this had obviously affected the way they perceived themselves.

Some had low expectations and ambitions for themselves. Several had an unrealistically low perception of their own degree of independence. They saw themselves as not having gained independence, when in their discussions it was apparent that they were in fact independent in some aspects of their lives.

One issue that was raised by many of the young people was their desire to be ‘normal’, rather than ‘different’. The young people made comparisons between themselves and ‘normal’ young people and stressed the importance of ‘fitting in’ and being part of ‘normal life’. Although this issue was often associated with school life, some talked about it in their current situation:

“They have to see somebody different and they stare, and I just do not like it. Like ... mostly, I am able to hide it, but not a lot of people can tell that I’m disabled, you know, ‘cos I walk normal – there’s a bit of a limp in my leg when I walk, but you know, you really can’t notice it.” (Fauzia)

In order to be seen as ‘normal’, some actively sought to hide their impairment from others. Elaine, who was doing work experience, had not told her employer about her impairment. She explained:

“I don’t want to tell her because, just in case she ... just in case she thinks differently about me.” (Elaine)

In wanting to ‘fit in’, these young black disabled people may be no different from their non-disabled peers. If this leads to the impairment not being accepted or being hidden, however, this can make it harder for the young person to obtain the support needed to lead an independent life. Khalid had hidden his increasing visual impairment and explained:

Khalid: “Well, well often my neighbours, they think that I’m normal, but I don’t want them to find out that I’ve got this disability.”

Interviewer: “Why is that?”

Khalid: “Just ... I don’t know why.”

Khalid hid his deteriorating sight through most of his school life, and this had a serious effect on his education:

Khalid: “Sometimes if the light was good I would manage OK. And I couldn’t read off the blackboard so I used to leave stuff out. I didn’t tell the teacher ‘cos I was ashamed to tell in front of all the other pupils.”

Interviewer: “Why was that?”

Khalid: “I didn’t want to be different from anybody else.”

Khalid had only recently, at the age of 19, started to receive the support he needed, by attending a disability resource centre to obtain the qualifications he had not gained at school, and undertaking mobility training.

It was clear for some of these young black disabled people that attaining a degree of independence had a lot to do with a particular level of personal determination. Some of the young people talked of the need to try things for themselves, to see if they could overcome personal obstacles. Others appeared to be people for whom overcoming challenges – such as passing a driving test or getting a job – contrary to the expectations of others, increased their self-confidence. For others their determination gave them the confidence to be

independent. Rifat explained how, by concentrating on her abilities rather than her impairment, she made achievements and gained in confidence. She talked of going away on holiday with her school, where she had coped better than she had expected.

The influence of role models

There was a shortage of appropriate role models for these young black disabled people. The majority were unable to identify any disabled, and in particular any black disabled, role models. As a result, only a few of the young people talked of role models and their impact. This is unfortunate, because appropriate role models could affect their aspirations by demonstrating what is possible for them as a young black disabled adult. Role models were seen as encouraging:

“... if you see someone else who’s black doing something else, who has learning difficulties then you think, like when you see them doing certain work and you think, ‘oh yeah’. Like you feel like, you feel really good, you feel really proud that there is someone else doing something.” (Jane)

A few were setting themselves up as role models for other young black disabled people, to show what could be achieved and to encourage others to try and fulfil their potential. One deaf young man was doing so quite intentionally, and having a strong effect on his younger sister, Saira, who was also deaf. She commented:

“I believe in role models. My brother at the moment is achieving a lot, he’s nearly there [with] what he wants to do. He wants to show all people that he’s a good role model – young people, when they grow up, what they want to do for the future. And I agree with my brother, I want to follow his aims.” (Saira)

Fauzia was the eldest female in her family. Through her actions – being independent by learning to drive and expressing her opinions within her family and community – she was becoming a role model not only for other young Asian disabled women, but for the women of her family in general.

The young people who mentioned this issue thought that black disabled communities, and black communities in general, need to provide more good role models.

The influence of race, culture, religion and community

We discussed the relationship between ethnicity and independence with these young black disabled people. Many discussed how important or otherwise it was to them that they were black. They also talked about their relationships within their own black communities as young disabled people.

Such discussions were dependent, first, on the ability of the individual to identify themselves as black and describe what this represented to them, and second, on the young people being able to compare their experiences as black disabled people with those of disabled people in general.

Race

Significantly, for some of these young black disabled people, their racial identity was not an issue they were in a position to discuss. There are several possible reasons for this. It is likely that some had not had the opportunity to discuss their racial identity and its impact on their experience of disability with their families or at school. Indeed, unless there were specific incidences – such as racism at school – the impact of their race and disability was not considered. This does not mean that they had not experienced difficulties because of their race, but it could be that, in not having the opportunity to discuss the issue at home or at school, they were not in a position to define any such experiences. This appeared to be the case for one young man whose parents were from Nigeria but who had been brought up by white foster parents. Kwame had little contact with black communities where he lived and virtually none with members of the Nigerian community. He was accepting of his situation and appeared indifferent to his racial identity. He described no problems related to his race, but it may be that he did not feel able to talk freely about this to us.

It may also be that race was not as important to these young people as their disability, or simply that it was not an issue for them since they had no direct experience of racism. On two occasions, parents present at the interview indicated that the young person had no awareness of race. Yet the young people in question were able to indicate differences in the race of the people who attended their day centres. Several young people mentioned race in relation to the day centres they attended, where, in many cases, they were the only black person.

Those who did talk about being black had strong clear views:

“It’s really important. ‘Cos I’m black and I’m proud of who I am and I wouldn’t let anyone else try to put me down. People can criticise at me but I wouldn’t take notice of it. I would I just block it out of my head and just carry on, just think, ‘Yeah, I can do this, I’m confident enough, I’m gonna do this’. And just really have that attitude really and, like, feeling good about, like, if you see someone else who’s black doing something else, who has learning difficulties then you think ... you feel really good, you feel really proud that there is someone else doing something else. But you see [...] people who are black and with learning difficulties [...] with other people who ain’t, they’ve got a bad attitude towards them. They don’t wanna know.” (Jane)

Culture

Others were more aware of the ‘norms’ of their particular culture and the effect these had on them as young disabled people wanting independence. For those young people who were deaf or hard of hearing, culture was a particular issue. Many deaf young people spoke of the difficulty in understanding their culture and in many cases, reconciling the differences between the culture of their English residential schools for deaf children and their own cultural identity.

Communication was a major issue for deaf Asian young people, living in families where some family members might speak in Urdu, Punjabi or

Bengali, but they themselves used BSL or Sign Supported English. Several could only communicate effectively in English. Roma is a 20-year-old deaf woman currently at college. Her response illustrated this difficulty:

“I mean it’s very different I [can communicate] with English children and their parents because they’ve got the same language, but with the Asian language it’s difficult, because if parents speak Punjabi or Urdu then we’ve also got the additional problem. So it’s very difficult because, I mean, children go to school and their main language is English but then when they get home it’s different.” (Roma)

For some of these young people, this lack of communication bought a new isolation and sense of being different from other members of their families. Jasbir talked about not communicating with his family when he came home from residential college:

“I don’t understand what my family are saying – I, I try to lip read them but it’s like they can’t be bothered with me really.” (Jasbir)

Reconciling these two worlds – English and Asian – proved particularly difficult when it came to asserting their independence. Some of the deaf young people, especially Asian women, spoke of adjusting to family life after school: coping, for example, with restrictions on visiting or with the activities they were allowed to do, and their parents’ expectations as to how they should behave. One young woman talked of



how she felt she was English at school but did not understand her Asian culture due to the language barrier.

It was evident that a strong cultural identity existed among these young black disabled people. However, the extent to which their culture affected their aspirations for independence depended very much on the relationship between individual young people and their families.

Religion

A small number talked about religion. Several young people regularly practised a religion: some attended the mosque, others were members of a Christian youth club and Bible study classes. Others wanted to maintain their religious practices but found that their impairments created practical obstacles to doing so. Learning the Koran was difficult for deaf young people because of the language barrier, while others found places of worship inaccessible to them as disabled people.

“I’ve haven’t had much contact with the mosque [...] recently because I’m not able to go to mosque and ... I find it too hard to reach, to the mosque for the ... with me it ... may need help. You’re supposed to be always clean when you’re going into a mosque, and I’ll have to take my clappers [callipers] off and [...] I can’t really [as] there aren’t any other shoes – I’m not able to walk in any other shoes.” (Imtiaaz)

Access to shared religious practice is an issue for these young black disabled people, particularly where religion is a main part of their cultural identity. It is the opinion of these young people, that the onus is on their own black communities to take active steps to enable black disabled people to take an active part in their religious community.

Relationships with their communities

There were varied views about the relationship between black disabled people and the black communities. Generally, the young people felt that black communities were supportive of their disabled people, but that most needed to

address their attitude to, and understanding of, disability.

A number of the young Asians held strongly critical views of their communities. They described a lack of awareness and acceptance in their communities which they put down to lack of information. They suggested that this also affected the understanding of disability by black communities. Several of the young people held views on how best to overcome the difficulties their communities experienced with disability.

“There’s not enough deaf Asian role models. That’s the real problem. There’s obviously a language barrier. They’ve got no deaf awareness. There’s an attitude. And there are other problems as well. I mean there’s no actual organisation specifically for deaf Asian minorities.” (Yousuf, a 22-year-old deaf Asian man)

“I think there should be a – I don’t think there is, but I think there should be – somewhere where, like, Asians can go, and, you know, talk about, you know ... discussing what their problems were.” (Riaz)

The impact of gender

Several of the young people addressed the issue of gender and how this related to their experience of disability and independence. Religion in particular, while it influenced the expectations of young men, had a far stronger influence on those of young women. Of the Asian women we spoke to, the majority described the effect of their gender and in some cases the added restrictions this caused in their lives. Many women spoke of the difficulty of visiting friends. They also had difficulty in going to clubs or groups for disabled people: many were not for women only, or their meeting times and places were seen as inappropriate – for example, a deaf Asian club held in the evening in a centre with a bar, which is not an appropriate environment for a young Asian deaf woman on her own.

Fauzia spoke of the multiple repressions she faced by reason of her impairment, her gender and her culture:

“Basically, it is because I’m disabled, but more I think ‘cos I’m a girl, an Asian girl – mainly ‘cos I’m a Pakistani girl – it causes that much problem.” (Fauzia)

Another young Asian deaf woman, Fatima, who currently held a part-time job and was studying for a degree, spoke along similar lines:

“... because I’m a woman and I’m Asian and I’m deaf, I ... you know, I feel I’m limited and it’s difficult. For example, in the Asian community women are not allowed to go out at night so that’s been a real problem for me. I feel that there’s a lot of discrimination. I’m ... I’m, trying to think of an example. A lot of people think that I can’t do a job because I’m deaf so I get discriminated against on all three counts.” (Fatima)

Cultural expectations were seen to affect how young Asian disabled women might realise any aspirations or ambitions they might have. While young Asian disabled men very often pursued further education, this was rarely the case with the young Asian disabled women. Some Asian men were equally aware of this discrepancy. Riaz, described the difference between the experiences of young men and young women:

“I think because the father would have more control over her. With a lad I think it’s different because, you know, you’ve got free rein really. With a girl I think you know, she wouldn’t be allowed to do half the things a lad would do.” (Riaz)

In many ways the experience of young Asian disabled women is no different from that of their non-disabled counterparts. For several of these young disabled women, however, the relationship with their family had a profound effect on the efforts to attain the most basic independence and realise their ambitions (see Chapter 4).

Of the six African–Caribbean and three African young disabled women, gender did not appear to be an issue with regard to their attaining independence.

Summary

Essentially, the young people in this study described a number of factors which influenced their perceptions of themselves and their experiences of independence. Confidence and personal determination were particular factors in helping a number of them to feel positive about themselves and their capabilities as young black disabled people. Role models played an affective part in encouraging some to develop and pursue independent lives. While they did not say much about the impact of their racial identity, their cultural identity was of significant importance to them. For Asian women in particular, it was important in defining the degree of independence they might attain. It is unfortunate that, given the small number of African and African–Caribbean young women, we could not make valid comparisons.

The young people interviewed show the interaction between their own perception of who they are and how families and communities respond to them. While the young people suggested that families and communities can be supportive they also highlighted a degree of ignorance. This evidence suggests that part of the agenda for future action must be how to change the attitudes in families and communities as this appears to be an essential part of support for young black disabled people’s independence.

For black communities, there are a number of issues that these young black disabled people felt need to be addressed in terms of developing an understanding of disability and providing support to enable young disabled people to live independently within their communities.

Ambitions

The majority of these young black disabled people had clear ambitions and ideas about their future. For some, factors such as family would affect the realisation of their ambitions, but most felt that they would achieve them. They talked about further education, getting work, a different life-style and providing a service to others. This chapter considers their views on achieving these ambitions, obstacles that would affect their plans and the extent to which these ambitions include moving towards independence.



Further education

Education was seen by many as the key that would enable them to achieve their ambitions, especially in terms of future careers. The younger ones (those aged between 16 and 19 years old) realised the need to obtain better qualifications or specific qualifications for their future employment.

“Well, like I said, I want to do this either modern apprenticeship or do this GNVQ advanced. If I end up doing the GNVQ Advanced I’ll probably go to uni, or set up my own business.” (Riaz)

“After doing this course I’m hoping to go on to training. And after my training I’m hoping to get a job in a clothing shop or something – retail working. And hopefully, hopefully about [...] five or ten years time be self-employed.” (Rifat)

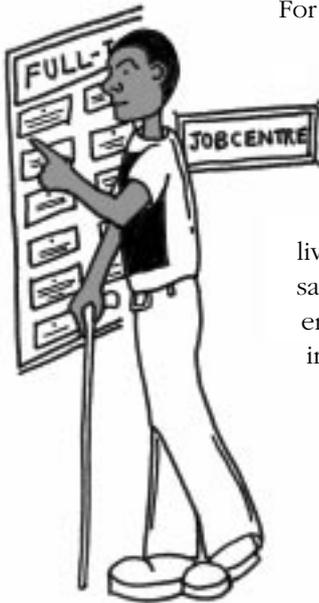
Both these young people were still in Sixth Form (Year 12/13) at school and were a sharp contrast to some others in their age group who had not thought about their future. One young man with learning difficulties who was at college did not

see himself achieving much apart from working in a warehouse.

Obtaining higher education qualifications was an aspiration for several but many saw their impairment as a barrier to this. For some this was the result of not having the correct information on what support they could expect while studying. The extent to which they saw further education as part of their future life strategy also depended on their previous experiences of compulsory education and the contribution it had made to increase their independence.

A number saw their impairments as an obstacle to their ambitions. Hosni wanted to work in the catering business, and recognised the need for further study. She explained, however, that this would be difficult because:

“... my writing is not that good; you got to write and you have to do all different things like that.” (Hosni)



For several of the young people further education was associated with attaining greater independence: being away at college or university and having more control over their daily lives. One young deaf woman saw going to university as enabling her to live independently from her family.

Getting a job

For most of these young people, future ambitions revolved around work.

Those with such ambitions held clear ideas about what they wanted to do and how they could achieve it.

However, for several, in particular those aged 20 and above, getting a job was seen as problematic, and it is here that racism was seen to be an issue. These young black disabled people acknowledged that they were restricted in achieving their ambitions and several talked about the disadvantage of being both disabled and black. Paul, described how prejudice could affect his chances of getting work:

“I think it’s gonna be difficult. I’m not sure. Being deaf and black will make it difficult, so I’m not certain about it. But I would like a job, you know, I don’t want a job cleaning or, you know, rubbish removal, I would like a good job. Perhaps at college or something like that.” (Paul)

When asked specifically how being black might affect his chances, he responded:

“Because white people ... there are mostly white people, and just having one black person, and deaf as well, um ... is gonna make it really difficult I think.” (Paul)

Aware of the role racism might play in undermining her future, Saira aims to challenge stereotypes by achieving her ambitions to be a minority representative in a particular trade:

“I want to be a famous Asian fashion designer for deaf Asian people. There’s one famous deaf white designer, but they’re white ... there’s no Asian, no Asian designer. Some black, but not deaf Asian. It makes me angry sometimes.” (Saira)

Through achieving this ambition Saira sees herself as doing what she wants to do, and also being able to educate the wider Asian community about deafness and deaf people’s capabilities.

A few of these young people do not foresee difficulty in getting work. One young man with learning difficulties currently attending a vocational course at college did not view his impairment as an obstacle. Tariq wanted to get a job as a mechanic. When asked whether his difficulties with spelling would be a problem at work, he responded:

“No, all I got to do is speak to them and ask them to spell something.” (Tariq)

Similarly, another young deaf man at residential college, discussing job interviews, explained that he would write the answers to the questions the interview panel would ask him. He did not see his being deaf as a difficulty for prospective employers.

The views of these two young men could be attributed to their youth and their lack of experience in trying to obtain a job. In the main, most of these young people saw their impairment as the main obstacle to finding work, since employers were seen as not welcoming to disabled people. Several young people intended to run their own business. For one young male wheelchair user, this was the only way he could see to avoid the prejudice of potential employers.

The type of work the young people saw for themselves varied. There were a number who planned to pursue skilled jobs, such as engineering, information technology or the building trade, nursery teaching, professional athletics, support work for deaf children and catering. However, a majority, particularly those who were over 20 years of age, were more inclined to talk about unskilled, low-status work in industry. There was a connection here between what they felt teachers and others

thought they were 'fit' for and the type of work experience they had undertaken while at school (working in factories, farms, shops, supermarkets) and on youth training schemes. While it is not clear whether other young non-disabled people had been given opportunities denied to these young people, their experiences seemed to have given them a strong sense of having only limited opportunities available to them.

A change of life-style

For some of the young people the future and their career ambitions were entwined with expectations of a different life-style. A number talked about different living arrangements which would enable them to be independent. For some this was living away from their family but with some support, be it sharing a home with friends, having help from a personal assistant or living on their own.

It was not always clear how the young people would achieve this since few of them knew how to get social housing or what other types of support they could obtain. Many young people had no regular contact with social services departments or other professional agencies. Pinky felt that changing her life-style by emigrating to another country would enable her to be fully independent. Not only did she see it as necessary to move away from her mother to achieve independence, but the support and facilities she had seen in America would enable her to have a better quality of life than she was currently experiencing in England.

For a number of the men and women alike, marriage was part of their immediate future. Asian young women tended to see their future plans in terms of marriage, very much dependent on their families' expectations and plans for them.

"... and one day if my parents introduce a man, I don't know, I'll judge for myself, but if my parents force me I'll leave. I want to organise my life, see to my life first. But hopefully ... my dream is to travel and meet the right man and if I save money I'd pay for it myself – nothing to do with my parents. I think that's fair you know." (Jasvinder)

While Dillip's remarks are typical of those young men whose future aspirations included a family:

"At [the] moment to look for job and that, and during the future I'd move out and that, get a bird [sic] and that, settle down, and that's about it." (Dillip)

Helping other disabled people

We have already seen how some of these young black disabled people hope to become role models and motivate others in similar positions (Chapter 2). Most referred to a lack of information about social care support outside the family, about the things to do and places to go to in each area, and specifically informal support for young black disabled people. Some had ambitions to provide information to others in their position. They aimed to inspire other young black disabled people to lead active lives in society.

Some hoped to address the needs of disabled people within the black communities. Tubassam described her hopes of establishing a group for Asian disabled women and encouraging them to be more active outside their homes:

"Hopes. Well I hope that really others would be able to do what I have been able to do as well because it's great you know. You don't want to be stuck at home you know, like I was, because you really ... you lose contact with everyone, you're just in your environment, you know home environment and er ... it's good to get out – I think people should get out and express their views as well." (Tubassam)

Becoming independent

For many of the young people, achieving their ambitions was seen as a positive aspect of independence. Those who wished to change where they lived felt that removing the well-meaning, but in some ways inhibiting, family support would enable them to do more for themselves. Many said that their parents were over-protective of them, and did not see them as adults: two young women described their parents as treating them like 'a baby' or 'a little

girl'. Many stated that their parents did not accept their transition to adulthood and their growing need for independence.

Several saw getting a job or undertaking further education as helping them to attain independence. Realising their ambitions would be a personal achievement, and would encourage others to see them as able to cope and be self-reliant.

Summary

Many of these young black disabled people had clear plans for their future. A future involving work, further education, changing life-styles and – for some – becoming role models for other young black disabled people. A number had

worked out ways of achieving their ambitions and were actively working to put them into practice. However, those who were older could foresee obstacles to their plans – for some, to be young, black and disabled was seen as creating considerable disadvantage in seeking employment. Partly as a result of this, several aspired only to the sort of work they had been encouraged to see as 'fit' for a disabled person.

Some saw education as an important factor in enabling them to achieve their ambitions and, perhaps surprisingly, this was also true of those who had negative experiences in school (see Chapter 5). Importantly, their previous educational experience also influenced the future they saw for themselves as black disabled adults.

Profile: Fauzia

Fauzia is a 25-year-old Asian woman living with her parents and two brothers. She has a physical impairment which prevents her from walking long distances, and sometimes causes her to have blackouts. Her family is from Pakistan but Fauzia was born and brought up in England. She is the eldest of the young women in her family and has a central role: among other things, she sorts things out for other family members, and acts as an interpreter.

She explained why she has this role within the family:

"They know I'll get my point across, I do get my point. But I know both you see, English and Punjabi, so they know I ... they prefer me 'cos I'm outspoken you see, they think that I will get my own way eventually."

She has a close-knit and supportive family:

"I've got a lot of people to turn to really, basically it's a big family, there are a lot of youngsters in the family as well – I think I have a lot of people to turn round to when I'm in difficulty."

A strong influence on her upbringing was her grandfather who encouraged her to do well in such areas as further education. Although very close to her family, she disagreed with their ideas about what she could achieve, and her future plans were very much tied up with their expectation of her:

"Yeah, I were thinking, I wanna do ... get a nice job, you know, what I would like, and [...] live on my own with my friends and outgoing with my friends, but they've [her parents] got other plans I think – they never mention them to me."

As an Asian disabled woman she talked of the difficulties she encountered because of cultural expectations and opportunities. Being a confident and assertive young woman, however, some of the issues she mentioned did not trouble her.

Her experience of mainstream school was a positive one in some ways.

"... that were good 'cos I used to get involved with able-bodied people as well, and there was the service of having a bus to help pick you up."

As a disabled person, however, she had also experienced difficulties.

"I didn't like the able-bodied school – everybody stares at you. They have to see somebody different and they stare, and I just do not like it. Like I ... I, mostly I am able to hide it, but not a lot of people can tell that I'm disabled, you know, you really can't notice it."

Moving to an integrated school, however, had been beneficial in terms of how she related to non-disabled students and how they related to her.

"I mostly just hung around with my friends who were disabled, but I did know a lot of, you know, able-bodied people there as well. But I think that were better 'cos a lot of able and disabled, like half and half, and they used to go around to see, and then they didn't ... you know, you weren't outcast, you know – if you're like one person, disabled person, I think you get outcast more."

She is currently undertaking a number of self-development and empowerment courses at college.

A number of things have influenced Fauzia's life, facilitating her growing independence. One important achievement was passing her driving test, which has changed her relationship with her family:

"1992 I passed, I think, March 19th – five years I've been driving, five years. That's one of my best moves I think I did – more independence and there's always an element that they always rely on me – I'd have to rely on them – my family especially, rely on me basically and I think that's made them more aware of my problems."

She described how she had felt on her first driving trip alone to town, to obtain her orange badge:

"And the feeling you had inside, you know, it's like, I've achieved something – really good, I really done something – see I can do it."

Her ambitions are to work in teaching, perhaps as a nursery nurse teacher. She also has plans to get married.

Education and independence

Education had helped to shape the ideas that these young black disabled people had of themselves and what they could achieve. Their own accounts of their education produced a wealth of varied and interesting information. Several factors in their education had influenced their concept of independence and the extent to which they expected to lead an independent adult life. This chapter will consider the type of education they had received; the impact of race; their perception of their education's usefulness; and the opportunities it had provided for developing independence.

Type of education

All of these young people had some experience of special education, mainly of a residential nature. The perceived benefits and disadvantages of special school education varied from one person to another.

Some who became disabled at a very young age and had always attended a special school accepted it. For some, it had been a positive experience to be in an environment where everyone was the same and understood each others' difficulties. Nikhil moved into special education during secondary school. He explained how attending special classes enabled him to cope better with the work:

"The special class, they were quite nice. They understood how ... about my difficulties." (Nikhil)

In asking how he felt about moving into a special class he said:

"As I said, I enjoyed it because the work was much easy, easy work." (Nikhil)

Rifat, had also found special education good for her needs:

"If I had gone into a mainstream school I would have found it hard, like, at first I had to get used to me disability because that was when it started to get worse – at around that age. And I were given support from the school, and my family as well, but school support were good. Like, helped me to build up self-confidence ... when I were younger I never used to talk to people, like I always kept myself to myself and when I started school I were encouraged to er ... joining in groups and things." (Rifat)

Other young people who became disabled during or just before their secondary education had not been sure what to expect from special education. Some had moved to special schools on the recommendation of their previous schools, but the implications for them in terms of the changes in school life had often not been explained. One young Asian woman with physical impairments, whose condition had been deteriorating towards the end of middle school (Years 5 to 8), moved to a special school, but felt she should not be there as she could walk and was not as disabled as the other students, most of whom used wheelchairs. Another woman with physical impairments talked of being scared when she started her special school because she saw other disabled people.

The controversy over special or integrated education for disabled children and young people is ongoing. The benefits of learning and

instilling a positive self-image in young disabled people, against the development of lower expectations and unrealistic preparation for an independent adult life, has been discussed by others (Flynn, 1989; Hirst and Baldwin, 1992).

The effect of special education on young people's self-esteem and self-image is an important issue. On moving into special education, several of the young people in this study noticed a change in what they saw themselves as capable of achieving. Some found that academic expectations of them were now lower. Those with learning difficulties appreciated that they were able to do the work with adequate support, but at the same time were aware that they were now given different and, according to some, easier work to do. These young people appeared to have a lower self-image in terms of their potential academic achievement and did not see the work they were now doing as helping them to get a job or live independently in the future. Several others were thinking of future work only according to what they had achieved at school and during their work experience.

For some of the young people special education made them feel less independent. One young Asian woman with physical impairments felt that moving to a special school had diminished her independence in that she was no longer able or expected to get her school dinner for herself but had it bought to her, and this made her feel dependent. When she started using her wheelchair she no longer saw herself as independent at all.

On the whole, those young people who attended integrated mainstream schools with facilities for disabled students had positive experiences. Most, however, experienced initial difficulties in adjusting to the change of school and experienced some prejudice from other students. Of the seven young black disabled people who were still attending school, five were at an integrated school, and were experiencing similar difficulties. Mumtaz spoke of the difficulty he found in adjusting from special school to integrated school because of his impairments:

“Like a, like I walk too slow [...] and people walk too fast, and at college they used to push you about. At [special school] no one walked fast there so you

can go fast, same speed as me.”
(Mumtaz)

One young man was particularly angry about his move to an integrated school and frustrated over his lack of choice in the matter:

Rajesh: “I was frustrated, but then I got used to it, innit. I mean you have to.”

Interviewer: “When you say you're frustrated, is that because you didn't want to come here?”

Rajesh: “Frustrated that I didn't want to come here and I had no choice in the matter.”

Interviewer: “Right.”

Rajesh: “You know, I had the rights, the rights were not there yet – the same rights as other people. I mean like other people they can appeal you know, and they said you can't even appeal.”

Fourteen of the young people were attending college, either mainstream or special colleges for disabled students. They were having positive experiences, and receiving appropriate support and the equipment they required: they were effectively independent. Two of the seven young people at school also attended a mainstream college for part of their course. They found they were treated in a more friendly manner than at school, with less prejudice regarding their impairment. According to Rajesh, “none of them takes the mick” and “the education is much higher”. They all felt accepted as independent young people by fellow students and teachers at college.

Education and race

A number, however, had experienced prejudice because of their race. Many were in a minority at special school and this was reflected in their school experience.

Two young women with physical impairments who attended a special school some distance from their home described what it was like for them:



“I felt – well, it was all right after a while, but 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.” (Pinky)

“You do feel like, oh why wasn’t there, you know, somebody your own age as well and who’s Asian, you know. You always see the white people but I used to get on with them as well [...] but you do think but why, where are the Asian people you know, sometimes.” (Tubassam)

None of the young people in the study spoke of having any help from teachers in overcoming their exclusion while they were attending predominantly white schools. Troyna and Hatcher (1992) have pointed to the failure of some schools to act because there is an assumption that racist incidents occur more in schools with higher black populations. They suggest, however, that within mainly white schools racism is often more complex and entrenched. A number of reasons why teachers have been reluctant to promote black students’ pride in their ethnic and cultural identity in such situations have been suggested. What is clear is that there is a need for developing good relations between all teachers and black pupils (Rejtman, 1998).

While having other black disabled people in school was not an issue for all these young people, those who lived in areas with large black communities often spoke of their need to have other black people around. Fatima saw a racial mix of students as an advantage when she

moved from the north of England to a school in London:

“... and it was a good ethnic mix as well, which was really nice, but up North it was all white children. Just very few children of other origins. But er ... [at the] new school the mix was really good, the teachers were much more aware – there were quite a lot of black, white Asian, deaf children. And I really enjoyed myself there – I learnt such a lot more.” (Fatima)

Although a number of the young people mentioned difficulties at school, such as bullying, it was not clear whether this was on account of their race or their impairment. Of those who mentioned instances of racism in school, none suggested that it was more of an issue for them than the discrimination they experienced from other students because of their impairment.

Students’ assessment of education

When asked about the usefulness of their education, the young people were very critical. Their schooling was seen in the main to have catered for their physical needs but to have failed them academically. Many had gone to a particular school because it was the most accessible and offered the best support for their needs as disabled people. A number, however, had experienced limitations to their academic learning.

Education for deaf young people

The young deaf people were especially critical of their education as a preparation for living independent adult lives. All eight had attended special schools for the deaf which used a combination of spoken and sign language. For some, the insistence on the use of spoken language (oralism) restricted their use of BSL, which they preferred and found much easier. Irfan, a 17-year-old Asian deaf man, describing his experience at an oral school, spoke of not understanding what the teachers were writing and how the teachers got very angry with him.

Some of these young deaf people suggested that the way they had been taught had limited their

academic progress. Many had left school with poor English as they had not understood what they were being taught. This was reflected not only in what ambitions they had, but in the steps some were currently taking to improve their poor educational achievement. One Asian deaf woman was still trying to improve her English at the age of 27. Others talked of insufficient support and the effect this had had on their education. Roma explained the difficulty in taking notes while lip reading or following a BSL interpreter:

“I mean it’s very difficult for deaf students to gain information from courses because hearing people can just listen and write, well we can’t do that.”
(Roma)

Supporting independence

Most of the other young people in the study, however, regarded the support they had received at school to help them cope with their impairment as beneficial and helpful in their personal development and their efforts to become independent. When asked what they had found useful at school:

“I learnt much there. It’s helped me a lot to develop my attitude and find out about myself.” (Imtiaaz)

“I can do everything mostly myself. All life skills, you know, like we do cooking. Not that I do any meself but, you know, if I had to I could do it. Basic life skills. I can touch type. I can use technology. I could probably wire a plug. I don’t know. What else is there...? Moving about – mobility.” (Riaz)

Low expectations

Nevertheless, some of these young people felt that the support they received from school sometimes inhibited their independence. Imtiaaz, who is a wheelchair user, explained how he was treated like a ‘kid’ by staff always wanting to help him without asking first if he needed any help.



As discussed in Chapter 4, other people’s perceptions contribute to disabled people’s image of their own abilities and capabilities. Many of these young black disabled people felt that their education had been stunted by teachers’ views of them as ‘lazy’ and ‘difficult’. These attitudes towards the young people were not useful and had affected their own perceptions of self-worth and their ability to achieve.

The young people’s apparent lack of achievement often reflected a lack of adequate support for them as disabled people. Rajesh, for example, was critical of the group support system in his classes, and was adamant that he was not lazy, as teachers had suggested:

Rajesh: “I say deep down I know what I’m doing even though they can’t see it. I mean teachers will tell you that I’m lazy and all that. If they’re telling you what they think of Rajesh, they’ll tell you he’s lazy and all that. And I’m not lazy so – I mean lazy at doing work, putting hard work in.”

Interviewer: “Why do you think they have that impression?”

Rajesh: “I can’t do ... I can’t do fast writing and all that, you know, maybe that’s why you know.”

Some young people said that their failure to obtain good qualifications was a reflection of their teachers’ low expectations of them. Several felt their schooling had not helped them to develop their full potential. Quite often the work was seen as unchallenging and therefore not equipping them for later life.

“The teachers knew I had poor English there but they didn’t support me, they didn’t help me to improve that. They really weren’t bothered. They

sort of focused on the students that were doing well and others were just left to play around and I felt that, you know, my abilities deteriorated when I was there. They didn't really take good care. They didn't help us polish up or improve ourselves." (Fatima)

Another young Asian man who used a wheelchair, and was currently undertaking a degree at university, talked of the lack of motivation while at school and how he had gained his qualifications in spite of the difficulties at school.

Research into the school experiences of young black non-disabled people suggests a similar pattern. The underachievement of black, and particularly African–Caribbean, Bangladeshi and Pakistani children, has been well documented (Klein, 1996; Gore, 1997). Stereotypical assumptions and expectations of young black people have been found to affect and be related to educational achievement (Wright, 1992, cited in German, 1996). Klein (1996) has highlighted how the OFSTED review of educational achievements found racial stereotyping influenced the type and extent of discipline imposed on young black people, compared with that imposed on young white people.

There are distinct similarities between the experiences of the young people in this study and those of young black people in general, and it seems almost certain that their teachers' expectations of them were based in part on their ethnicity.

Opportunities for independence

Although a significant number painted a dismal view of their educational experience and how it prepared them for independence, there were also several who had had positive experiences.

Work experience, participating in group trips and mobility training, were some of the positive opportunities for independence made possible by school for many of these young people. Some of the opportunities not available to them at home were provided at school or college. A young Asian visually impaired man described the last two years at his special school as the most enjoyable of his entire school experience:

Interviewer: "What was it you liked in those two years? What was happening?"

Sohail: "That I would be independent."

Interviewer: "Right, what were you doing?"

Sohail: "I was shopping for school and doing it myself."

Sohail also talked about the enterprise initiative that he was involved in, buying and selling foods, trophies and other items to make money for school trips.

For some of these young black disabled people the education they received improved their self-image and enabled them to develop greater independence. One young physically disabled woman spoke of the confidence she gained while at school. Going to her special school not only enabled her to come to terms with her impairment, but also helped her to become more independent and realise she could cope with challenges, such as going on holidays, undertaking research for college and work experience.

Many had learnt some life skills which would help them to move on to an independent life after school. These included practical skills which would enable them to look after themselves, such as cooking, shopping and household chores, and skills which would help their personal development, such as preparing for work, budgeting and managing money. Those who went to residential colleges had been to training flats and found this valuable. A young deaf man who attended residential college said that this approach to education gave him greater independence and freedom than he had at home, and enabled him to do what he wanted to do: going out with friends, travelling around town and going to nightclubs.

Although many of these young black disabled people described aspects of their education which they felt was not useful, a number of them had the opportunity to develop their independence while at school. They had learnt some life skills that their educational establishments deemed necessary for independence, although how they saw these

developments as contributing to their independence was questionable.

Summary

The young people varied in their estimation of the contribution made by their schooling to their personal development and independence. Teachers' perceptions had influenced their own sense of worth and their educational achievements. Deaf young people in particular were critical of the education they had received and the way it had prepared them for independence and employment. While many of the young people had had opportunities to be independent and develop the skills needed for independent living, others had not.

A number described how racism, and being labelled as 'difficult' or 'lazy', had affected their educational achievements. For some of them, the low expectations of teachers had influenced their ideas about what might be possible for them in the future.

Attending predominantly white schools had created difficulties for a number of them – not only in terms of their ambitions but also their perception of themselves as black disabled people. Some of these young people appeared to have difficulty in their awareness of themselves as black people (see Chapter 3). This is likely to raise some issues for them in terms of their expectations of gaining employment, and being able to fulfil their ambitions.

While in no way dismissing the effect of these factors, the question arises as to how different the negative experiences of these young black disabled people of education are from those of young black people in general.

An important aspect of independence is not just in being able to define it, but in having the opportunity to develop and experience it. We have already looked at some of the concepts of independence endorsed by many of these young people. Independence for them referred to self-reliance, to achieving without any support in doing so. By these criteria, these young black disabled people did not see themselves as independent, even though for some of them independence will always necessarily include an element of support. We have already seen that some of these young people wanted to live on their own, with support, in order to live independently. But the majority, however, saw using support as being dependent.

Education appeared to have given contradictory impressions of independence to them. On the one hand, schools and colleges appeared to foster a particular concept of independence: of self-reliance, making an effort and the development of relevant skills. On the other hand, schools also appeared in many ways to restrict young people's ability to attain and express their independence.



Profile: Riaz

Riaz is a 17-year-old visually impaired Asian man. He lives with his parents and is attending the Sixth Form (Year 12/13) at an integrated school, where he studies a GNVQ Business course. He is the youngest of the three sons in the family and both his brothers are living independently in their own accommodation. One brother is partially sighted and the other is blind. Riaz is extremely active both socially and in pursuing outside activities.

His education has been mainly in special schools. From the age of five his sight deteriorated and he attended a school for blind children. Riaz understands what is happening with his sight and explained:

"I stopped wearing my glasses because I didn't like my glasses anyway, and they just slowly went, bit by bit. I didn't get no explanation of what might happen."

School provided continual support and equipped him with many skills which he found useful.

"I can do everything mostly myself. All life skills, you know, like we do cooking. Not that I do any meself but you know, if I had to I could do it. Basic life skills. I can touch type. I can use technology. I could probably wire a plug. I don't know. What else is there...? Moving about – mobility."

Although he mentioned some difficulty with other students relating to him as a blind person, overall, Riaz's education in an integrated environment has been a positive experience.

He is an extremely confident and independent young man, talking often about overcoming challenges, such as the need to move around town on his own: "I saw it as a challenge. I knew I'd need it one day."

He is living a very independent life, which he defined as: "Having the freedom of choice."

His family have been his main influence in developing such independence, although there have been differences between how his mother and his father related to his growing independence:

"I think if it were up to my mum she'd like wrap me up in cotton wool, because it's not really, you know. I get to do what I do – what I want, and my dad he like [gives me] more support."

He has little contact with social services but has a very strong support network of friends and family. Riaz is happy living independently in the family home and talked of how he could do just the same things whether he was living on his own or with his family, for example, making decisions and managing his money.

Riaz has done work experience in a business environment, of which he said:

"I enjoyed it. I got to do all the things which the employees there were doing, so it was good."

His hopes for the future are:

"Well, like I said, I want to do this either modern apprenticeship, or do this GNVQ Advanced. If I end up doing the GNVQ Advanced I'll probably go to uni, or set up my own business."

Work and independence

As part of independent living, paid work was an aim for many of the young people in our study. Having financial independence was associated with having control, deciding when and how to spend their own money, fulfilling their ambitions or contributing to their everyday family life. This chapter examines young people's attitudes to, and experiences of, work, and the obstacles they saw to obtaining it.

Attitudes to work

There were many reasons for wanting to work. Work could be seen as something which would enhance self-esteem and enable young disabled people to realise their own value. Through work, a person could gain a level of self-fulfilment, as well as benefit from meeting other people. Those working could also challenge the stereotype of disabled people not being able to work. Young disabled working people could become role models and offer encouragement to other disabled people. Notably, work was linked to an expectation of self-reliance, of having responsibility – a part of growing up along with getting married and having a family.

Current government figures indicate that disabled people are half as likely to be economically active as non-disabled people. There are 5.3 million people of working age (16 years and above) with work-limiting long-term impairments in the UK (15% of the population) (ONS, 1998). There is no actual indication of the number of people who are capable of working or who want to work.

Almost all the young people in this study wanted to work. They held specific ideas about what they wanted to do, which were most often

influenced by the work experience they had undertaken or stemmed from their own ambitions. The majority clearly indicated their aim to have a skilled job, rather than being channelled into jobs which were seen by others as appropriate for disabled people (see Chapter 4).

Having control over your own money was an important part of being independent which many linked to getting work. While most expected to be able to find work, they could foresee difficulties in doing so.

Experience of work

The majority of the young people had had some experience of work. They had attended Youth Training Schemes (YTS), participated in work experience placements, had been in paid employment including summer jobs, or undertaken voluntary work.

Paid employment

Those who had been in paid employment were few. Paul had held summer jobs:

“I have had a job – three jobs in the past. One at a West Indian food place and [factory], I was making boxes, it was good wages that, but they were mostly white people there, but I made some friends there. But I've had to give that up because of me college work.” (Paul)

Only two of the 44 young people were currently in paid employment. Both were women employed by disability organisations. Fatima

worked part time for an Asian Women's Group in an advice/advocacy role. Jane worked part time as a development worker for an organisation for people with learning difficulties. In talking to these two young women, it was apparent that working for disability organisations made them much more aware of issues of discrimination against disabled people. Such organisations gave useful access to information about disability rights and independent living issues. Both women enjoyed their work and spoke of their roles in the organisations:

"I work as a Development Worker for [a disability organisation] and we've not long recently developed a pack [...] and it's about making information accessible for people with learning difficulties, and people who are blind and deaf as well...." (Jane)



"So, I ... I went and started the job and I realised that the Asian Women's Group – some of them were very poor and the women that were there they had poor English and they lacked information and confidence and knowledge. They had difficulties accessing things and I mean one of the major problems was communication, and because signing wasn't their first language that was difficult as well for them. So I had to advise them and advocate for them and encourage them and we offered them some training...." (Fatima)

Work experience/Youth Training Schemes

The main opportunity the young people had had to find out what working would be like was through work experience. The type of work

undertaken covered a wide range, including working in shops, a building society, a farm, a factory, a warehouse and offices.

Some of the young people had had good placements – often related to the work they wanted to do in the future. Riaz thoroughly enjoyed his placement in the accounts section of a building society, which involved using the computer and dealing with individuals' accounts. He experienced no difficulties and developed good relationships with staff. This placement was closely linked to his ambition of working in a business environment.

"Because I wanted to do business and accounting, and it just ended up being there." (Riaz)

Seema had explored the possibility of office work:

"Yeah, I used to, I used to, I went to a place where, you know, worked over down in town and I went to learn office work for two weeks, just to know whether office work was what I wanted to do. And I used to get £5 a week." (Seema)

Yousuf had worked with young children around identity:

"You know, it was a challenge for me. It was a new experience. I was going 'round different schools. It was all development skills for experience. Something to put on my CV. It was better than just sitting back and doing nothing." (Yousuf)

For some, work experience contributed to their own personal development through enabling them to gain particular skills. Positive experiences enabled the young people to come to terms with their impairments and negative self-perceptions, resulting in a boost to their self-esteem. Rifat described the effect on her as an individual of her work placement in a supermarket:

"I felt on edge. When I did work experience I felt like I'd increased me self-confidence 'cos there, and like, I coped with everything. When I came

back into school I felt confident. I felt I could do things. I don't have to think, 'oh I can't do this', or feel not too sure, if I should do it or not." (Rifat)

Seema talked of her YTS placement and how much more independent she had felt since she did it:

"I found everything much easier and I wasn't relying on other people to do it for me, I know that I can do it." (Seema)

Several others, however, had mixed feelings about the experience. Hosni had done mainly catering as work experience at school and through the day centres she attended.

"I didn't know I work in the catering section I just worked with them. I went with a member of staff from [the centre] anyway and a client came with me so is like working in work experience. It is alright working with them because you know someone is there with you, but if your friends not there you don't know what to do." (Hosni)

Support while working is an important issue, particularly if it is not clear where the support will come from when the young person gets paid work. Support, or lack of it, also influenced some people's attitudes to work and their ability to cope. Jane had a difficult experience working in a busy reception section of a hospital:

"... I couldn't do filing 'cos I didn't. I tried to do it, but I couldn't and, like, the stress as well coming in and out of there. I couldn't handle it." (Jane)

The level of support varied, with some people having support workers throughout their placements while others did not mention having had any.

The degree of choice also affected some young people's experience of work placements. A number were critical of the way their placements had been arranged, and their lack of choice in the matter.

Rajesh: "I worked in an office. I didn't even want to work in an office."

Interviewer: "So how did you end up doing that?"

Rajesh: "I ... somebody chose it for me."

Interviewer: "Right."

Rajesh: "See I wanted to do, you know, design classes, you know, somebody who designs – they said no."

Several others spoke of similar restrictions in deciding about work placements. They had limited choice about the type of work they did and the organisations they worked for. In one of the research areas, the three young people we spoke to all did one work experience placement in a building society.

One young man did not even have the opportunity of doing work experience at school, as his headteacher felt it would not be advisable because of his impairment.

Type of work experience placements

One young woman was involved in voluntary work, at a disability resource centre. She undertook secretarial and administrative work one day a week to add to her portfolio for a college course she intended to take.

Others had worked unpaid in family businesses, which tended to be in retail. However, most of the young people's work experience placements were in factories or shops. For example, Sohail had done packing as a work placement in a factory:

"Packing, checking to make sure things weren't faulty before they packed them away. I was working, I was the only deaf person with a whole factory of hearing people with no mental stimulation whatsoever. And I was bored and everyone else was bored and we all hated our work and I thought well, you know, but they put up with it, I thought well if this is what you're gonna put up with fine – I'm not. And I was quite angry and I said 'I am not satisfied with doing this, I don't want to do that' and the teacher would say 'oh no, no you have to go on'." (Sohail)



Hosni had had work placements over a number of years within the service industry. She had a current placement at an industrial workshop, which prepared disabled people for work. She undertook various types of packing work and described her 'sticking job':

"They do like now, know how they fold shirt like, into there you have to fold the thing up, put the labels on, and I have been doing that for a couple of times. I have been doing sticking the, you know the glue you stick things on." (Hosni)

Others had had similar tasks.

"Hoovering, sweeping up, I learned delivery, putting stuff on shelves, do dusting, work behind the till, that kind of stuff. Cutting wood." (Pervez, of shop work)

"You know the carton, put all the soap in – that is what – I went there." (Malik, a 19-year-old Asian man with moderate learning difficulties, of factory work)

For some, the type of work placement – for example, in the service industries or low-status, poorly paid sectors – appeared to influence their own perception of the type of work they could expect. Wanting to do shop work was not unusual. When they talked about the job they wanted, many of the young people could think only of the type of work they had previously experienced through work placement or the family business.

If experiences of work are restricted to particular types of work, or there is limited involvement in the planning and choice of placements, how then will young disabled people be able to estimate their own potential? As Mumtaz aptly said about his placement:

"Yeah, it was all right, you know, but I mean if you don't like where you want to work you can't work there though, can you? I mean you have to like what you're doing." (Mumtaz)

We have already highlighted the clear ambitions some of these young people had. Some were fortunate to have work placements closely linked to their ambitions; for others, their placements helped form their ideas about what they wanted to do. However, given that the majority had placements doing shop or factory work, this raises the question whether young black disabled people are directed into particular types of work. This may affect their own image of what they think they are capable of. Are they therefore limited from the outset as to what they are likely to achieve?

Obstacles to gaining work

Because I am a disabled person

Some of the young people thought that there were few, if any, forms of work which they were capable of obtaining and doing. Many saw only limited opportunities for work, because of both their impairment and the negative attitudes of other people. Families, friends, teachers and others influenced their view of what was possible for them, and placements in low-status work no doubt reinforced this view.

A number of the young people were concerned about their impairment and the difficulties they might have in getting a job package which included suitable support. Dillip described unhelpful responses from employers when he had applied for jobs. Nevertheless, he felt that getting a job was part of becoming independent and saw no difficulty in obtaining work.

"I think I would be alright I think. I'd cope with the work and that." (Dillip)

However, he was one of only a few. Several others indicated that their impairment and a lack of support would be an obstacle to working:

"So catering it's difficult because ... if I do catering I can't do the till because I'm not very good at that. Some people are, but I'm not." (Hosni)

The effect they felt their impairment would have on their ability to work depended on their individual circumstances. In addition, some were concerned about the attitudes and responses of non-disabled people. As previously mentioned (see Chapter 2) some intentionally hid their impairment because they felt others would have a different view of them and their abilities.

Not all felt their impairment would be an encumbrance in working with other people. Many had found the people they worked with friendly and helpful. One 20-year-old deaf man, Haider, actually had his impairment highlighted through wearing a badge, and found this helped other people to relate to him appropriately:

“Had deaf written on badge on shirt. Hearing people good – helped me. Thought it helped because people knew I was deaf... I felt good. If people looked at me saw badge says ‘I am deaf, please ask hearing man’.” (Haider)

(Although this last part of the badge had a questionable message.)

All but one of the young people had been disabled since birth. Abdul who had become disabled later in life, no longer saw working as within his grasp. He had previously worked but was not currently doing so because of the debilitating effect of his impairment and deteriorating health. He spoke of his frustration at not working:

“But I wish I feel like to go, but can’t hide those things what, you see ... because you have to tell them that ‘have you got any disability problem?’ I can’t hide this, I have to admit that, you see. But I wish I have a good job and someone will keep me, you see, but now I’m married, I’ve got two kids as well, two daughters, you see, so there’s nothing, you know, I can do. I mean I haven’t got a choice I have to stay on that, on the dole.” (Abdul)

This view was an exception. The majority, who had been disabled from birth, had a more positive outlook and a greater determination about getting work.

Self-perception

As outlined earlier, although there were a number who aspired to working in skilled jobs, a significant number still saw themselves as capable of obtaining and doing only low-status, poorly paid work. This may be the consequence of the type of work experience they had undertaken shaping and influencing their ambitions.

The process of getting work

For some disabled people the process of getting work itself may be an obstacle to overcome. Several of the young people highlighted the difficulties they envisaged because of their impairments. A main issue was finding employers willing to accept disabled people as valuable members of the workforce. Zafar highlighted employers’ attitudes to his impairment as the main barrier to getting a job:

“You know, although they have, as I say, they’ve got these laws, it doesn’t work like that. Whether they accept people into their workforces is up to them. They always find excuses for not ... you know, they’ll say you haven’t got the ... you haven’t got the qualifications or you’re over qualified or whatever, they’ll find an excuse.” (Zafar)

The solution he had worked out to this problem was to set up his own business in the multimedia field.

The need for support and information

Most of the young people had some idea of the process of getting work: applying for a job, completing an application and the interview process. Nevertheless, those who had had paid work in the past had obtained their jobs through other means – usually through friends or family connections.

In general, the young people did not have information about the support available at work. They knew nothing about possible assistance and support through the Access to Work and Personal Assessment and Counselling Team (PACT) schemes. This was not surprising, as

they had little idea of what support might be available to them generally.

Haider was at residential college and talked of his plans to get a job in car bodywork. He would communicate at his interview, he said, by asking interviewers to write down the questions and responding in writing. He was not aware of any other support he could get, apart from asking a member of his family to interpret for him. However, providing a BSL/English interpreter for deaf people at interviews is one of the ways in which PACT can help disabled people.

Jane and Fatima, on the other hand, showed what a difference good support systems could make to disabled people in the workplace. Both were currently working and had had good experiences of work. As we have noted, however, both these women worked for agencies specifically working with disabled people. As employers, these agencies appeared more likely to make the working environment accessible and provide adequate support to ensure workers were actively involved in their work and were fulfilled in their jobs.

“When I first started working here I was a voluntary worker. And everybody here really supported me, really everybody in here ‘cos we support each other really, and I got to learn things. I got to learn about different people who have different experiences and we learn from each other. And we work as a team to improve things as well, and that builds you confidence so I can make me more independent and being more reliable.”
(Jane)

All had some experience of work. Most were critical of the type of work placements they had undertaken, in predominantly low-status, poorly paid sectors. Others highlighted their lack of involvement in deciding about such placements as an issue that had affected their experiences of work. Some young people had ambitions, but it is questionable how their work experience placements had prepared them for work and what opportunity such placements had given them to pursue the careers they wanted.

While most wanted to work and envisaged work as part of their future, they also spoke of difficulties in achieving this. Some had identified ways of overcoming these difficulties, but others felt that it was impossible for them to work because of their impairments. However, most lacked relevant information, especially about possible support at work, and this affected their aspirations of working.

Summary

The young people in this study valued the idea of work and saw it as a positive way of making independence possible and expressing their independence. Through working these young people wanted to enhance their personal development and actively contribute to society. They also thought that they would be challenging stereotypical assumptions about disabled people.

Social care agencies

Social care agencies have a vital role in supporting the needs of young disabled people and their family. In this chapter we examine the role of social care agencies and what young disabled people can expect from them. We then outline the contact the young people in this study had had with these agencies. In this assessment, we concentrate mainly on their relationship with social services departments, but also discuss their involvement with health practitioners and community organisations.

Role of social care agencies

Several pieces of legislation outline the responsibilities of local authorities in assessing and meeting the needs of young disabled people.

The 1970 Chronically Sick and Disabled Persons Act, the 1986 Disabled Persons Act and the 1989 Children Act outline the responsibilities of social services departments to provide ongoing care and support. To prepare young disabled people for independent living, social services departments are expected to work alongside local health and education authorities to develop a transition plan for young disabled people moving into adult life. Inter-agency working is necessary to meet the objectives of the transition plan.

The 1990 NHS and Community Care Act states that local health authorities are responsible for assessing and providing for the health needs of disabled people. Health practitioners work alongside education and social services and other agencies in carrying out this role.

Voluntary and community organisations offer a

variety of supportive services for both the young disabled person and their family. While larger community organisations often have a more significant role in providing these services, many smaller community organisations provide specific and invaluable services to particular groups and local communities. Often, community organisations supplement statutory care provision, with social services departments actively using community care to fill the gap in their existing services, for example, for short-term residential placements.

Black voluntary organisations have generally provided invaluable supportive social care services to black communities (Butt and Box, 1997). The benefits of providing appropriate services to black communities have been recognised by statutory service providers, who have supported specific services (both through use and sometimes funding) undertaken by the black voluntary sector.

Contact with social care agencies

Generally, young disabled people and their families expect care provision and support to be provided mainly by social services departments according to the young person's needs. This provision includes personal care, specialist equipment, day centres and other services.

However, such expectations were not evident among the black disabled people in this study. A significant number of the young people said they had little or no contact with social care agencies, particularly with social services departments.

The young people did not use many services, whether provided by their local authority or by

other agencies. The main support service highlighted by the young people was the transport they received to attend school, college or a day centre. Many were not aware of who provided this service, only that it was provided by 'the council'.

Whatever the interaction with social services departments previously, it appeared to have decreased as these young people grew older. Most of the young people referred to support workers at school and contact with other officials during their education. Very few referred to assistance from social services department, even though the majority were obviously known to social services since the departments had helped us to contact young people to take part in this project.

Services used by the young people

Education

Local education authorities have a responsibility to assess and provide for young disabled people's special educational needs while at school and in further education. For all the young people in this study, education services were the ones with which they had most contact: all talked about the support they received during school.

Social services

Most had had less contact with social services. A small number spoke of at least one social worker and had had some regular contact with them. This tended to be for specific purposes, such as assistance in applying for Disability Living Allowance or in obtaining equipment, such as flashing lights to alert when the telephone rang in the case of one young deaf woman.

A few did not know whether or not they had a social worker. Zafar described how he had contacted his local social services department to find out about specific equipment for his impairment: he discovered that not only had he not been assigned a social worker, he was not even known to the department:

"No they, they, when I was about seven I had, I had contact with them a couple of times. I got this, this orthopaedic bed

off them and that was the only time I had contact with them. Then when I got in contact with them about five, six years later they never knew, you know, I told them 'I've been seen before but it's quite a long time', but they've never heard of me before." (Zafar)

Only recently had Zafar been allocated a social worker.

Health services

For several, contact with health professionals appeared to be more important. Several saw community nurses or speech therapists on a regular basis. Healthcare professionals played particular roles such as providing information; for one young man his occupational therapist was more important than his social worker in helping him obtain equipment. These professionals, as well as addressing their health needs, often provided some form of outside contact for those young people who had few social links.

Community organisations

Several of the young people used community organisations as part of their support systems. These organisations were not necessarily branches of major disability organisations, but often small support groups. Usually, initial contact with community organisations had not been made directly by the young people, but possibly by a link-worker from a day centre.

"How did I know where to go? Because, you know, day centre, member of staff in day centre they take me out during the week, yeah." (Pervez, about the Mind drop-in centre)

The young people who went to community organisations tended to use services specifically targeted at black people. For example, the young Asian deaf people in one local authority regularly attended a deaf club for Asian people within a Deaf Centre, rather than make use of the main facilities of the Deaf Centre.

Although the majority of young people had little contact with community organisations, it was apparent that many felt the need for a support group specifically for black disabled people.

Reasons for limited contact with social care agencies

There are several possible reasons for this low level of interaction between the young people and social services departments in particular.

The initial contact with any social care agency had been made by parents on behalf of the young person. As they grew older, the young people were often not aware of the full extent of services provided, and it is therefore not surprising that they would have little contact with these departments. Recent work suggests that the main service provision by social services departments for disabled children and young people is respite care (Morris, 1998). If this is the case, it is not surprising that these young people were not using social services as this was not what they needed to enable them to make a smooth transition to an independent adult life.

It was apparent that, for these young people, there was a change in the way they related to social services departments and themselves, whether directly or via their families, once they were 19 years of age. Generally, the older disabled people, aged 20 and over, had less involvement with social services departments. This may have been because they were not used to the responsibility of contacting departments directly themselves. It is also likely that their previous experience with social services departments had influenced their ideas about social services. Some of the young people said that they had received little assistance from social services and felt that the support being offered was not necessary or appropriate.

The geographical location of some departments had made some services difficult to access. A deaf Asian woman was particularly critical of the reduction of services for disabled people in general in her area, as well as the move of the social services department from a central location. She pointed out that the department was no longer accessible to her, and criticised the lack of information she had received about the move. She had had to make alternative arrangements to get the support and information she needed.

Because most of the young people received the support and care they needed from their immediate family, they saw less need for outside

support, and tended to rely on informal care arrangements as much as statutory care services.

Some did not think that statutory care services – particularly personal care – were acceptable. Javed, who had multiple impairments including diabetes, lived in his own home. He did not welcome the idea of personal assistance from anyone other than his mother and explained:

“I’m happy with my mother doing it for me.” (Javed)

He went on to explain that living near to his family for support was important:

“Well, yeah, I think that would be important, because, I get the attention of my mother for my care. If she wasn’t next door I mean she wouldn’t be able to do that. Well she would, but then that would mean separating from my father.” (Javed)

This reaction may illustrate a lack of knowledge about the service provision available. Lack of information was particularly evident in talking to these young people about Direct Payments and personal assistants. Most had no knowledge of Direct Payments, and how this might affect them. Given that some of the young people expressed an interest in living on their own with support, information about Direct Payments schemes to organise this support would have been beneficial.

Only one of the local authorities had recently started a Direct Payment scheme, but even this one had not targeted information to young disabled people.

It has been illustrated that the lack of appropriate service provision from social services departments has led to the reliance on informal care for disabled people and their families (Morris, 1993a). While



many of the young black people in our study were happy with current family support, the situation is in no way ideal. It can bring stress to families, as well as potentially preventing young people from leading independent lives while they are not aware of the support available to enable them to do so.

While the responsibility of social care agencies is clear, in practice many black disabled people are not receiving adequate services. It has been illustrated that local authorities are not providing appropriate services to meet the needs of young black disabled people. (Baxter et al, 1990; Begum, 1992; Azmi et al, 1997). While black community organisations “have the tools required to provide an appropriate service, such as speaking the same language” (Butt and Box, 1997), this does not rule out the need for such services in existing service provision by statutory authorities. Unwieldy and bureaucratic departmental processes also have an impact on young disabled people’s access to social and healthcare support (Johns and Fielder, 1995).

Summary

Adequate support is essential to enable young people to live independently, though the amount of support required varies according to the individual. These young people showed a lack of awareness of the support that social care agencies could provide for them. It is clear that social services departments need to review how they work with young black disabled people. In particular they need to address information needs, such as ensuring that young people know the names of the professionals – social workers or healthcare professionals – involved in their care. Lack of such knowledge affects the ability of the young people to plan and run independent lives.

Profile: Tubassam

Tubassam is a 24-year-old Asian woman currently living with her mother, her brother, her sister-in-law and their two children. She was born in Pakistan but has lived in England since she was four years old. She has been a wheelchair user since contracting polio at the age of four.

Tubassam went to a special school for disabled children some distance from home. Overall she talked of having a good school experience, but being the only Asian person in the school was an issue for her. She went on to a special college and later an integrated college, where she was also one of only a few Asian students.

It was while at college that she learnt independence skills – some through sharing a flat with another disabled student. Of this she said:

"That was really good actually, it, you know, gave you an idea of how life really is, you know, from outside college. And first of all you're used to like school and college, you know, and then you're always relying on someone aren't you, and after college you feel you want to, you know, do something for yourself as well – not rely on anyone else, and make your own decisions. And that helped."

She is the Chair of a newly formed association for disabled Asian women, which has been set up partly to encourage women to meet and not stay isolated at home, as she had done for some time. She currently attends a disability resource centre. This is an opportunity for her to meet others and join in activities; she also uses the centre for her information needs. She has very little contact with her local social services department.

Tubassam recently moved into a house that has been adapted for her needs and talked of what this meant to her:

"This house is more, it's more ... it's got the needs for the wheelchair, it's got a lift and everything so I can do everything for myself. The kitchen is ... the work tops are low for me, the sink is low so I haven't got any problems with now ... you know, I can do everything for myself."

Getting a transfer to such a house involved a long wait, however, and was difficult because the housing department did not understand her needs as a black disabled person, and offered her accommodation away from the rest of her family. This would not have been appropriate as her mother and brother are her main source of support.

Tubassam sees herself as leading an independent life:

"I am living with my family but I'm still independent you know, I don't rely on them, I drive a car, if I need to go out, I go out, I don't rely on anyone."

She has had a lot of encouragement from her family in developing herself and describes how important it has been to be able speak for herself and make her own decisions.

While she is independent in her everyday life, Tubassam has not had any work experience and is not sure if she would be able to get a job.

Her hopes for the future very much reflect her own experiences: not being able to get about much, having difficulty in accessing places she wants to visit, and being isolated at home:

"Well I hope that really others would be able to do what I have been able to do as well, because it's great, you know, you don't want to be stuck at home, you know, like I was, because you really ... you lose contact with everyone. You're just in your environment, you know, home environment and it's good to get out. I think people should get out and express their views as well."

Conclusions

In this final chapter we draw out the findings of our interviews with 44 young black disabled people. From this we identify some of the policy and practice implications for those who work with young black disabled people. Equally important, we highlight the need for black families (and black communities) to look at their own views on disability and the abilities of their disabled children.

What is independence?

The progress of most young people to adulthood is marked by growing independence, but our interviews suggested that for a majority of the young people interviewed the situation was more complicated. Most made it clear that independence was important to them, describing independence as being able to 'do things for yourself' as well as the 'freedom to do things that I want to'.

For those with learning as well as physical impairments, there were ways of identifying what they meant by independence and describing its importance to them. Nitin talked about his time in a group home and how he enjoyed being there. He also talked about going shopping at Tesco's with his own money and having to decide what he should buy to eat. He clearly registered his disappointment that he was no longer at the group home and had had to return home. He told us that he had spoken to his social worker and his father about returning to the group home, and that his social worker was trying to arrange it.

Other young people talked about being independent in different ways. For some it was

a question of doing things without help: travelling on their own, learning to drive or spending their own money. For some it meant having the right to choose and make decisions, such as deciding what to do in the daytime.

The young people in the study felt that one major benefit of being independent was the greater confidence they developed as a result. They were also able to change the way other people thought about them. Families especially could see what they could achieve, such as learning to drive.

However, some of the young people wanted to emphasise that they were happy with their lives and did not want anything to change. It appeared that some thought that our questions about independence suggested a need for change in their lives. While we made it clear that this was not our intention, it did bring out an important point: that for some young people any discussion of change in their lives was a cause for some anxiety.

What is independent living?

Most young people in the study described independent living as living on their own. Many who had lived away from the family home talked about what was good about living in their own home. However, they also spoke of the difficulties, with some telling us that they were lonely at times. In addition, they pointed out that the lack of necessary support was a problem. They contrasted this with the support and care from their family which they could call upon when they were in the family home.

This emphasis on family support was also demonstrated by those who talked about what would help them live on their own. A number said they would like to live near their family. This, they believed, would allow them to get the type of help and support they needed. This desire to remain close to the family was expressed by young deaf people in particular – although they often described the frustration of not being able to communicate with family members, they still saw family support as vital.

It is worth noting that most of those interviewed were happy in their current homes and said they were living independent lives. Some, however, did feel that the present situation was difficult. While only a few young people said they were unhappy, all of those were young women. Jasvinder had returned home from spending most of her teenage years in a residential school and found it very difficult to cope with the demands of her family – particularly their control over what she did with her time. Another Asian woman was using her time at a college for disabled young people as a release from the restrictions of being allowed to socialise only with family members. Elaine did not say that she was unhappy with her family, but was quite clear that she wanted to move out into a flat or house of her own.

On the whole, however, young people felt they did not have to live on their own to be independent. Many suggested that *how they lived* was as important as whether or not they lived on their own. Being able to make decisions and do things for themselves was an important part of being independent. This, they felt, was equally possible living in a place of their own or with their family.

It was also clear from the interviews that what young people think about independence is influenced by a range of factors. Our report explores these and we present our conclusions in the remainder of this chapter.

Being black and disabled

There have been many discussions among black people about identity, how we describe ourselves and people like us. Much of the discussion in the 1980s was about children from black communities who had been in care and

whether they were encouraged, by the families they were living with, or the residential homes they were living in, to understand that they were black.

In the 1990s a number of black disabled people challenged the disability movement for failing to see that black disabled people may have different experiences from white disabled people. They have also challenged black people for their failure to recognise that there are black disabled people who are being mistreated by other black people.

Being disabled

Our interviews asked the young people how they described themselves and their families. Some people knew what was different about them and why they were seen as disabled; others did not. Not everyone accepted being described as disabled. Deaf young people especially did not feel they were disabled.

Many young people talked about not wanting to be different from other young people and wanting to be 'normal', and some hid what was different about them. Others, however, knew they needed help and support as a disabled person, and were angry that they were not receiving it.

Ethnicity, religion and racism

Outside their community

Most of the young people in the study recognised that they were different from the majority of people in this country: many were able to identify other children who were like them at school or recognised that there was no one else like them there. One young Caribbean man noted that there was no one like him at his school but that there were two Asian boys who were also deaf; one became his best friend. Another Asian deaf man noted that because at school he had the best English out of all the Asian children, any new Asian child would be immediately placed with him. A couple of Asian deaf women noted the difficulties they experienced in adjusting to life at English residential schools and then readjusting to life at home.

Some who had been in special schools talked about being treated differently from other students there because of their ethnicity. These young people were still trying to understand why this had happened. For the most part, however, few had much to say about being treated differently because of their ethnicity.

Within their communities

Some young people talked about how they were treated by their own communities. Most of those who spoke about this said that their community was supportive, but several also said that black communities needed to understand more about disability and deal with their own prejudices.

Saira had come to believe that she was ‘thick’ because she was told so by other people in her community, including her family. She now says that she realised herself that she was not ‘thick’, and that she was “just like a hearing person” except she could not hear. A number of these young people saw the need for black communities to deal with these prejudices: only then will they be able to support young black disabled people and enable them to develop more independent lives.

There was regular discussion about religion, particularly among the deaf Muslim young people. Asian young people explained how important it was to them to take part in their communities’ religious observances. Some, however, had difficulties in doing so because of their impairment. They suggested that their communities should try to make religious observances more accessible.

The contrast between the interviewees’ observations on being disabled and on being Asian, Caribbean or African highlights the fact that while being ‘different’ in terms of ethnicity is widely recognised and often not seen as a ‘problem’, being ‘different’ because of an impairment remains difficult for a number of young people. Some of the young people (mainly those who are deaf) concluded that they are not disabled, while others had attempted to hide their impairment.

This contrast is partly the result of their relationships with their families, who have managed to promote a positive sense in them of their ethnic identity at the same time as being

negative about their impairment. This negativity had been reinforced by some of the schools and some of the teachers, as well as by the wider community.

People’s own opinions of themselves will inevitably be influenced by what other people’s opinions are and their capabilities are likely to be affected by what they think they can do. Both these points appear to be amply illustrated by our interviews. In this context, the call by some of these young people to black communities to examine their prejudices about disability is seen as vital because it would help disabled people to build a more positive self-image.

Aspirations for the future

Though the young people may have had varying views on the problems caused by their impairments, our interviews showed that all held clear ideas about their future. Many had plans and ambitions and were actively working towards realising them. These plans involved work, further education, changing life-styles and, for some, becoming role models for other young black disabled people.

The younger ones, in particular, saw gaining qualifications or going on to further education as necessary to achieve their ambitions. Some looked forward to going away to college and being more independent. Some, however, did not think further education was possible for them, either because they had had bad experiences at school or because of their impairment.

Many wanted to get a job. Several, however, could foresee difficulties in getting work because they were both black and disabled and felt they would be treated differently because of this. Most had a clear idea of the career they wanted to pursue. A large number, however, seemed to think they could only get certain types of jobs – working in shops or warehouses – because they were disabled. This was the sort of work they had done on their work experience placements, and many felt that this was all they were ‘fit’ for.

For some, a role model was motivating, although most of the young people did not know of any disabled or black disabled high achievers. All

said that black disabled role models would be an important encouragement for their own development and could show others what it is possible for black disabled people to achieve. A few young people wanted to become role models themselves. In this way their achievements could encourage and motivate other young black disabled people.

By fulfilling their ambitions, some young people saw themselves as becoming more independent. They would be able to show family and friends how independent they were – they could get a job, they could go to college. Other people would then see them as being able to cope and lead independent adult lives. Most of the young people wanted their lives to change in the future – they wanted similar things to other young people, such as getting married, having children, moving to a place of their own and getting a job.

Education

Education and the experience of schooling up to the age of 16 was something that dominated many of the interviews we conducted. Some who had been to special schools talked of the good points: being the same as everyone else, and getting the support they needed. Others, who had started special schools later in their school life, had found it difficult to adjust. Some felt the support they got from special schools actually made them more dependent.

Some of the young people had been one of only a few black disabled people in a mainly white special school. These schools were often far away from their home. They talked of being treated differently by teachers and other students because they were black. They said they did not get any support at school to find out why they were treated differently and what they could do about it. Some had been bullied at school.

Those who had been to integrated schools for disabled and non-disabled children had experienced difficulties. These were mainly from other people teasing them because of their impairments. However, there were some who had had good experiences mixing with non-disabled children.

When assessing the effect their schooling had had on them, some felt they had been taught a lot and it had helped them to be independent. They talked of developing themselves personally, gaining confidence and learning skills such as managing money. Work experience placements had been another positive aspect of their schooling – for most this had been an opportunity to be independent, to find out about work and see what it was possible for them to do.

These positives, however, have to be contrasted with the negative view most of the young people in the study had about their schooling. Many said it had not been useful because it had catered more for their physical than their academic needs. A number of the young men, both Asian and African-Caribbean, recalled being constantly described as ‘naughty’ and ‘lazy’. Furthermore, some deaf young people had poor English because of how they were taught at school, and were having to learn English later in life. Other deaf people were angry that they had been discouraged from using sign language. Most importantly, virtually all the young people had left school without any formal qualifications, with some suggesting that their schools had never expected them to get any qualifications, so had not bothered with them.

The experience of going to college (post-16) had been a positive one for the most part. Some, mostly Asian women, had struggled to convince their parents to allow them to go to college. Others had struggled with schools or colleges to allow them to attend or to secure the support they required. Nevertheless, those who went to college had had good experiences, in contrast to their experience of school. Many said that colleges had the right equipment to help them with their studying as well as support workers to help them learn.

Continuing with some form of education often figured in the lives of these young black disabled people. It appeared that the negative experiences of school did not deter them from continuing their education. Furthermore, many recognised that education had an important part to play in helping them to achieve their ambitions.

Social care agencies

Social services departments and health services are the main organisations with a responsibility to offer care and support to disabled people. But at the time of this study, our interviewees said they had little or no direct contact with social services departments. Some reasons for this lack of contact were:

- it was the parents who originally contacted social services, not the young people;
- they had not had good relations with social services departments in the past, and did not want to contact them now that they were older;
- they did not know what services were available and where to go for help;
- they relied on their families for their main care and support.

A number recalled having had contact with social workers and social services help while at school. As they got older, they seemed to have less contact with social services. Many did not even know if they had a social worker. Overall, more were in contact with health service staff, such as community nurses or speech therapists. Some told us they obtained information from health staff and described them as their friends. Others, however, described the limited information that they got from doctors, particularly on the state of their health and (when this was the case) why their impairment was getting worse.

The lack of direct contact between social services departments and these young black disabled people is perhaps surprising. While we need to treat this evidence with caution, as it was not always clear that the young people differentiated between the professionals they came into contact with, it must be a matter of concern that even those who were aware of social services departments said that it was their parents who were in touch with them. This also meant that if these young people had a transition plan, most were unaware of it and its content.

Community organisations

Only a few of the young people had support from community organisations. Those who were deaf noted that they rarely attended clubs for

deaf people because the other people there were older than they were. A young Asian man with learning difficulties attended and enjoyed a resource centre funded by social services, but run by a voluntary organisation. A few others attended groups for young people and some went to groups for young black disabled people. Many felt it would be good to have a support group just for black disabled people.

Work

Most of the young people had positive attitudes to work, and all had had some experience of it. Most had done work experience placements while at school. These placements had varied, but most had been in shops, factories or warehouses. One had also had a summer job, while another had been in full-time employment in a restaurant before the onset of his impairment.

A few young people enjoyed the opportunity of doing work experience and getting to know what working would be like. They had had placements related to their future career plans. Some found that working helped them realise their potential and feel independent.

Several, however, had disliked their work experience because they were not given a choice of what to do or where to go. Others had disliked it because of the nature of the job they were doing, such as packing work in a factory. These young people felt that this was the only type of job they could do if they were to get paid work.

Some had hidden their impairment during their work experience so that the people they worked with would not treat them differently from other workers.

The two young women who currently had paid jobs were working for disability organisations. They had much more information about disability rights and available support. On the whole, however, most others felt that employers would not be supportive and would be unwilling to give disabled people a job and even with legislation to help disabled people, many still felt it would be difficult to find work. Some might need help to do a job, such as assistance with reading and writing, but did not think they

would be able to get such help. They felt employers would not want to pay for it.

While a few young people decided to become self-employed in order to overcome the difficulties of getting work, for the majority this was not an option. Many felt that people did not have enough information on how to get a job. They did not know what support they could get, such as help at interviews, help in writing or help while at work.

Final remarks

The young people we interviewed came from a range of backgrounds and, although the majority were living at home with their birth families at the time of the interview, a number had been in residential schools, some were now away at college or university, and others had had experience of living in group homes or on their own. Only one of the young people was married and he had children of his own.

Almost all the young people had brothers and sisters, but only a small number of those brothers or sisters were also disabled. The experiences of non-disabled siblings were usually different: they went to different schools; they left school with qualifications; they were more likely to have full-time jobs. However, some of the young disabled people had done things before their brothers and sisters, including learning to drive, getting a computer and going to university. For one young Asian woman, learning to drive had opened up many new opportunities and transformed the way she was seen by her family. Fauzia was the first woman in her extended family to learn to drive and she soon became the centre of the extended family network.

While there were other stories like Fauzia's, it is nevertheless the case that our interviews generally show young black disabled people being ambitious, but having these ambitions frustrated or ignored. Their families sometimes stood in the way of their ambitions out of malice (one father said to us "I don't know why you want to interview her – she is stupid"), but most often from a desire to 'protect' their disabled child (one young man said "my father would do anything for me, I just wish he would let me do it first"). Other people frustrated these young

people's ambitions by having low expectations of them. Nearly all the young people particularly criticised teachers and schools. A number of the young men described running battles with their schools and said that they had often been described as 'troublesome' or 'naughty'. Most distressing was the fact that the young people thought their teachers had had very low expectations of them. Possibly as a consequence of this, many left school with no formal qualifications. Many were currently struggling to overcome this educational hurdle and find ways of getting qualifications that might be a route to work.

Those who went on to pursue other forms of education generally had better experiences, even though for some they were pioneers because the colleges and universities they attended had rarely had any disabled students.

Our interviews revealed that most of these young people did not have the relevant information to help them achieve independence. Hardly any knew of new provisions, such as Direct Payments, which would help with independent living. Most people did not know where to get help or information if they wanted, for example, to move into their own place or go to university.

However, most of the young people knew and understood what independence meant and identified many ways of demonstrating independence. For most of the young people, independence was about control and choice and for some this also involved living separately from their families. Most, however, intended to live in or near their present family home.

Further research

There is always a temptation at the end of any research project to suggest that more research is needed regardless of the outcome of the present study. However, with this study some new lines of enquiry are suggested, beyond recognising that further work with African–Caribbean young people is still needed.

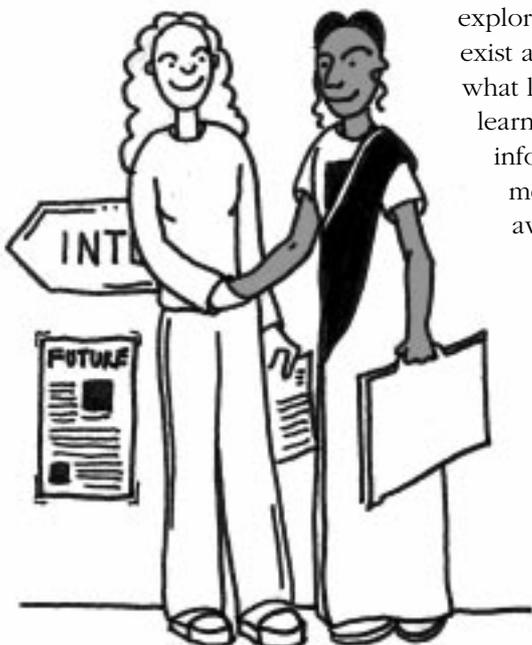
The first is a need to place the findings of these interviews in the wider context of the families of these young people. This would allow us to explore how this group of young people's experience is different or similar to those of their

siblings. Furthermore, for these young people their relationship with their families, in particular their parents, was a constant theme of the interviews. But this study only presents views from one side of this relationship. Importantly, if some of the recommendations suggested below are to be achieved, some exploration of the wider families' views is needed.

The second line of enquiry is to understand what the issues are for those who should be providing support to this group of young disabled people. From our interviews there seems to be little contact between social care providers and young black disabled people, beyond social services departments knowing that these young people are out there. How can these agencies support the promotion of choice and control for young black disabled people? These interviews do not tell us whether social care providers have made efforts (for example, by providing information) and that these have failed, or whether no effort has been made.

The third line of enquiry is that our interviews show that for many of these young people independence and independent living is more than just about the formal aspects of support (education, work, housing, personal care), but is also about informal support. Role models that foster ambition, or could make them feel more positive about themselves, were considered to be important. A number of these young people talked about the lack of informal support, but others also pointed to things that had worked, in particular disabled support groups specifically for young black disabled people.

It would be worth exploring where these exist already to see what lessons can be learned to make this informal support more widely available.



Future action

This study is explorative and thus we need to be cautious in making over-ambitious claims for what it suggests about future action.

Nevertheless, some recommendations seem to be reasonably clear.

Young black disabled people need to be specifically supported to articulate their needs

It is not sufficient to subsume their needs under the umbrella of young disabled people. This is not because young black disabled people's needs will always be different, but because it is clear that their needs are not always the same as other young disabled people (the continuing importance of families in notions of independence and independent living is one possible example of this).

In supporting young black disabled people to articulate their needs we must also be careful not to substitute their views with those of their parents or families. Our interviewees' descriptions of how much control they have over money they receive shows how important this is. In addition, supporting young Asian disabled women is a particular issue.

Information needs to be made more readily available to young black disabled people

Our interviews showed that on a range of matters such as further education, money and benefits, support with independence and independent living, these young people were reliant on others for information. Their lack of knowledge about Direct Payments should be of particular concern for those promoting choice and control.

Relying on family members appears to be an inadequate route of getting information to these young people. Equally, relying on some of the disability support groups is insufficient. What are needed are specific ways of providing accessible information to the young people themselves and a range of service providers need to think about how they could do this. Schools and colleges may be one way of providing information to young people directly. However, some of the negative experiences with schools would suggest that other changes would also need to take place for this method to become effective.

All professionals need to assess how effectively they are working with young black disabled people

Teachers and lecturers need to consider whether their expectations are so low that they are damaging the ambitions of these young people. Those involved in selecting and supporting work experience need to pay particular attention. As the interviews make clear these young people are not just 'fit for the factory'.

Those professionals who have the role of supporting young people with independence and independent living need to assess how effectively they do this with young black disabled people. The lack of knowledge about Direct Payments may be explained by a number of factors, but it may also be a sign that these practitioners have not ensured that all the information gets through.

Practitioners will also need to ensure that their concept of independence and independent living is one that focuses on the promotion of choice and control. And that it is likely that the expression of this choice and control is likely to be different from one person to the next. This may mean for some that independence is closely tied to their families.

Black families and communities need to embark on action which explores their understanding of disability and challenges any prejudices

While these young people point to the supportive nature of their families and their communities, they also point to a number of difficulties, in particular, the lack of understanding of disability. In some instances this is demonstrated by over-protectiveness, but in others it is expressed through ignorance or abuse.

The evidence of prejudice against disabled people should not come as any surprise and it is certainly not specific to black communities, but the need for action is clear. Black families and communities need to specifically address how they treat black disabled people and any prejudice or stereotypical views must be challenged.

By taking these and other steps we can support young black disabled people to achieve their ambitions.

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Appendix: Collecting the information

We carried out interviews with 44 young men and women from across England. This Appendix sets out our methods of locating young black disabled people to take part in the study, and collecting information from them. It also describes our techniques for making sure that we understood each other.

Finding our interviewees

To find young black disabled people we selected four local authority areas from across the country. Three had an above-average number of black people for that area: for instance we selected a local authority in London with 28% black population (the average for London is 16%). The fourth area we selected was a county with a comparatively small black population, because we wanted to see if the young people there had different experiences from those living in areas where there was a larger proportion of black people. Therefore, the young black disabled people interviewed came from four local authority areas in England: a city council, two county councils and a London borough.

We asked social services departments, educational establishments and voluntary organisations (including black-led ones) to help us contact young black disabled people. We wrote to these young people either directly or through the agencies asking them to come forward. Some agencies and authorities were more supportive and responsive than others to our needs. In the area where local authority support was not very good, we had to put in significant extra effort to contact any young people. However, we were able to secure the cooperation of a number of young people (and often their families) to complete 44 interviews.

Our interviewees

At the time of interview the youngest of the interviewees was 16 years old, and the oldest was 30 years old. In total we interviewed 18 teenagers, 25 people who were in their early to mid-20s and one who was 30 years old. More young men than women agreed to be interviewed: of the 44 interviewees, 16 were women and 28 were men.

Although we selected areas of the country where there was a range of ethnic groups, we were not able to interview as many young people of African–Caribbean and African origin as we had hoped. In total we interviewed 12 Caribbean and African young people, 32 Asian, none of Chinese origin.

Of the 44, 35 lived at home with one or (in most cases) both of their parents. Three lived in residential accommodation, two lived in group homes, one was at university, one had his own council house, one lived in a privately-rented house and another was in long-term foster care. Some had previously lived in other settings, for example, in residential schools when they were younger. A couple had been away to university or college and had now returned home, while others had been in group homes, but returned to their parents' home.

The majority of interviewees had learning difficulties, but we also spoke to young people who had motor impairments, were deaf or hard of hearing, or had visual impairments. Some had multiple impairments.

The range of learning difficulties ranged from mild to severe, and one man had Asperger's syndrome. Other young people had a variety of

physical impairments. For example, one had Friedreich's ataxia and several were paralysed due to contracting polio at an early age. Others had cerebral palsy and muscular dystrophy. Of the three people who had visual impairments, one had no sight and one person had retinitis pigmentosa, which results in restricted vision, particularly at night. One young woman had dual sensory impairments.

Several of the young people had limited communication skills or used non-verbal communication methods. The young people used a variety of descriptions to explain their impairments. These were not necessarily the same as those used by care professionals.

Importantly, there are solutions to these problems, which meant that we were able to carry out interviews with young black disabled people with a wide range of impairments. One of the solutions is to use in-depth interviews. With in-depth interviews we were more able to implement some of the best practice for carrying out research with disabled people. In particular, such techniques gave us the ability to ask appropriate questions and understand their response based on a knowledge of "the person and their life" (Simons, 1994).

The interviews were all tape recorded and then transcribed. This resulted in over 400 pages of transcripts.

The interviews

All the interviews were carried out in an environment agreed by the young people – this was mostly in their homes. Most young people made the decision themselves to take part in the interviews, and sometimes in agreement with parents. In one instance, however, a young woman and her family disagreed about her involvement. The young woman decided she wanted to be involved and the interview was arranged to take place at a day centre she attended.

An issue for this project was whether we should carry out interviews with people who had learning difficulties. Beyond the possible problems in communication, some studies of response bias have suggested that people with learning difficulties automatically say 'yes' to yes or no questions, or that they choose the last of the options offered in multiple choice questions, and are less likely to respond to open-ended questions (see Simons, 1994, summary and review of Sigelman et al, 1981). But as Simons argues, using work carried out by Conroy and Bradley (1985), any bias may be more a function of coping with a "lack of power, experience or not knowing about the interview or the interviewer", than of their learning difficulties (Simons, 1994).