

## **Chapter 7 (In 'Cabbage Syndrome': The social construction of dependence, Colin Barnes (1990) The Falmer Press, pp. 157-186)**

### Integration into the Community

This chapter is divided into two main sections. The first concerns the environmental and social barriers to integration which confront people with disabilities in the community and illustrates the extent to which the Contact users are disadvantaged in these areas. The second covers their leisure and social activities outside the units and highlights the level of social isolation many experience in the domestic sphere. The data underpin the importance of the day centres as a nexus of social activity for participants and show that the majority do not expect to leave the system in the foreseeable future. I conclude, therefore, that to varying degrees many of these users will become dependent on the day centres and as a result their disadvantages will be compounded.

### Barriers to Integration and the Contact Group

I will first outline the major environmental and social barriers to the integration into contemporary society of people with disabilities, and secondly, show how these obstacles are encountered by Contact users when outside the day centres. The data is based both on observed examples of individual and group interaction and on user interviews. Where appropriate I will draw attention to the visible changes in users' behaviour during these encounters and show how these experiences reinforce their dependent status. Howe (1978) has identified six major barriers to the integration of people with disabilities into society. They are architectural, attitudinal, educational, occupational, legal and personal. Howe illustrates the first of these, which includes all aspects of the physical environment including braille notices for the blind, printed signs for the deaf, correctly sited elevator buttons, modified public transport accessible to people with limited mobility and access to all public buildings, by discussing the problems associated with government buildings in America. He records, for example, the number of schools not adapted for pupils in wheelchairs and shows how getting legislation for an architecturally barrier-free environment through Congress is considerably easier than putting it into practice. A similar difficulty exists in Britain. This is evident from the increasing number of guides put out by organizations representing people with impairments which show that access to many public buildings and amenities such as

theatres and libraries, which the non-impaired take for granted, is almost impossible without prior notification to the appropriate authority. The report by the Committee on Restrictions against Disabled People (CORAD, 1982) stated that many people with impairments perceive access difficulties as 'the most fundamental cause of discrimination' .

The basis for Bowe's second category, attitudinal barriers, is historically and culturally determined and enmeshed in the ideologies and policies of national governments and institutions (see Chapter Two). As noted earlier, we sanctify the minority of 'super-cripples' who transcend the limitations of their impairments but relegate the majority of like-situated individuals to a life of relative poverty and social isolation. These practices perpetuate the negative attitudes associated with disability among the general public. They include perceptions of the disabled as 'less than whole' (Dartington, Miller and Gwynne, 1981), a threat, objects of ridicule, pitiful, or eternal children (Hurst, 1984). Usually on first encounters people with overt disabilities are viewed by the non-impaired as abnormal. Consequently these interactions are problematic for both parties. In a study of data derived from encounters between the able and the visibly impaired, Davis (1964) identifies a two-stage process before normal relations ensue. The first stage is designated as 'fictional acceptance' and denotes the initial interface where distant cordiality prevails and the question of impairment is overlooked. The second stage occurs when the subject is brought out into the open and the disability enters the conversation in a 'non-stigmatizing way'. Only then can normal relations proceed and it becomes possible to admit to the interaction the restrictions which the impairment imposes. Bowe comments on covert rejection occurring since politeness does not permit overt negative reactions and describes experiments which show how the non-impaired espouse opinions that they do not hold to avoid giving offence when conversing with the disabled. He notes the falseness and awkwardness of these encounters. Other sources have drawn attention to the extent of the 'does he take sugar'? syndrome (Hurst, 1984) where remarks are directed to a third party and not directly to the person with an impairment. It is also important to note that overt hostility and rejection are not uncommon. Individuals with visible impairments are occasionally refused admission to public amenities because of their impairments and sometimes made to feel unwelcome by entire communities (Mills, 1988).

Educational barriers are those which operate to segregate children with impairments from their non-impaired peers into special schools. This applies in further and higher education as well as in basic schooling. And despite the plethora of criticism directed at the policy of segregation

because of the consistent failure of special schools to provide an adequate education, both the number and percentage of children in special education in the British Isles continues to rise (Booth, 1981; Barton, 1986; Tomlinson, 1985). Barton echoes Tomlinson in suggesting that the gradual expansion of special education can be best seen as a political response to a critical dilemma facing the education system and society .generally, namely, the need to control the expanding surplus population (Barton, 1986). The situation in further and higher education is equally dismal. Thomas (1982) maintained that many universities and colleges were inaccessible to disabled students. In a recent survey of provision for students with disabilities in' further and higher education, Richard Stowall provided evidence to show that this is still the case and reports that,

Despite the recommendations of the Warnock Committee in 1978 that all colleges should have and should publish, a policy on the admission of students with special educational needs, fewer than 1 in 5 colleges have a formal policy. Those that have tend to be the major providers for students with special educational needs (Stowall, 1987, p. ix).

Obstacles to paid employment, Bowe's fourth category, are many and various. The Disabled Persons (Employment) Act of 1944 laid a framework for the provision of employment rehabilitation and resettlement schemes and provide legislation which gave people with impairments legal rights to paid work b obliging those employing more than 20 workers to recruit at least 3 per cent 0 their workforce from the disabled persons' register (Oliver, 1983a). Despite these legal rights, unemployment among the disabled remains disproportionately high when compared with that among the non-impaired. Prosecutions for non.. compliance with the Act against employers are few. There have only been ten since the Act became law in 1944. There is substantial evidence to suggest that even within government departments quotas are not filled (Thomas, 1982).

There are conflicting explanations for this situation. It has been suggested for example, that many people with impairments do not register as disabled because of the stigma associated with disability and/or because they feel that registration can harm their future prospects. One source has suggested that the majority of civil servants who work in the employment resettlement and careers services believe that the Act is unworkable and that they favour the repeal of its mandatory features and a return to a voluntary policy. Organizations representing: the disabled, on the other hand, take the opposite view, arguing that the Act is too weak and should

be strengthened. There is also clear evidence to show that government officials consistently attach more importance to the views of employers than they do to the representatives of the disabled population (Stubbins, 1983). In a society dominated by the economic rationality of the market place, the disabled are among the most vulnerable sections of the community. Even when employment is offered it is often low-paid demeaning work, and the match between abilities and occupations is frequently unbalanced. As well as unemployment many people with impairments have to contend with under-employment (Thomas, 1982).

Bowe's fifth barrier relates to the legal obstacles which confront disabled people. On a similar theme Thomas (1982) has asked why it took so long for the Chronically Sick and Disabled Persons Act to reach the statute books and why an important report such as 'Integrating The Disabled' was published as late as 1974.

There is also a gap between legislative intent and action. The much vaunted Chronically Sick and Disabled Persons Act, the cornerstone of statutory provision for people with impairments, sought to give people with disabilities the right to live in the community by providing the appropriate support services. Local authorities were obligated to perform two specific tasks which were (a) to inform themselves of the number and needs of disabled people in their area and (b) to publicize their available services.

Section 2 of the Act lists services which should be provided for those whose needs have been assessed. These include practical assistance in the home, recreation facilities, free or subsidized travel, social services support for carers and families, aids and adaptations and so on. It is regarded by some, notably Topliss and Gould (1981), as a charter for the disabled', nothing less than a public testament to the social rights of disabled people. They argue that the passing of the Act and its subsequent publicity has increased public awareness of the problems associated with disability and changed attitudes toward people with impairments. Others contend that this unprecedented media attention has had the opposite effect. Public interest in the subject has waned, it is suggested, because many non-impaired people now believe that all the needs of the disabled are met by the Act (Simpkins and Tickner, 1978). The reality could not be further from the truth.

In 1979 one commentator maintained that Section 2 of the Act was in effect only Section 29 of the National Assistance Act of 1948 'writ large' (Keeble, 1979, quoted in Oliver, 1983a). The same author notes that while the Act

promises much, careful analysis of Section 2 reveals that provision is not mandatory and nor is it free. The Act's implementation has been hindered by a number of factors such as the reorganization of local authorities and the health service during the 1970s, the successive economic 'crises' and the discouragement by central government of local authorities' attempts to initiate parts of the Act, particularly those which involve a large capital outlay. Consequently there is much regional variation in services.

One attempt to clarify this piece of legislation, conducted by the Royal Association for Rehabilitation and Disability (RADAR), concluded that despite some limited success in specific areas, it is clear that given the current economic climate and the uneasy relationship between central and local government, the Act is neither implementable nor enforceable (Cook and Mitchell, 1982). Subsequent developments, namely, the successive re-election of right-of-centre governments with a definite bias against state-sponsored welfare systems, an avowed intent to reduce state spending and an ambivalence toward local authorities which borders on paranoia have exacerbated these problems still further. The result is that some authorities have begun to withdraw services which were hitherto provided (Ernstoff and Howe, 1988).

Thomas (1982) maintains that while there are still legal barriers confronting disabled people, such as the requirement on some job applications for applicants to disclose specific illnesses such as epilepsy, the most important hurdle is the complexity of legislation rights, allowances and claiming procedures. Claiming welfare benefits is now so difficult that a new professional known as the Welfare Rights Officer, has emerged to act as intermediary between the layman and the law (Simpkins and Tickner, 1978). The situation has become progressively worse in recent years with the tedious successive changes to the already complex state-sponsored social security benefit schemes, and the introduction in April 1988 of the Community Fund, which marks the end of statutory payments and a return to a means-tested discretionary system (Lynes, 1988).

The final category in Bowe's (1978) typology is the personal barrier. He comments that adventitious disability results in problems of daily living, reduced social status, decreased income and lowered perceptions of self. Life-long impairment, he argues, is frequently associated with an inferior education and preparation for life as well as segregation from the non-impaired. Bowe contends that the stress of coming to terms with the harshness of the non-impaired world makes the congenitally impaired

attribute their misfortune to their impairments. Within this context, 'passing' as normal or non-impaired becomes an over-riding preoccupation.

Goffman (1968) used the term 'passing' in his analysis of the interactions between the 'stigmatized' and the 'non-stigmatized'. It refers to those situations where the former on initial encounters with the latter deliberately conceal information about specific aspects of their social identity which they feel will be discrediting. From this perspective to be disabled is to be a 'shamed' person. However, while there are a number of techniques for passing available to individuals with less obvious impairments, such as epilepsy, passing for the overtly physically impaired is more problematic.

Thomas adds a further dimension to Bowe's typology, the professional barrier to integration. It is the result of what he terms the 'professionalization of handicap' .

Handicap has become the happy hunting ground of many professional interests. Handicap is the province of the medical specialist, the educational psychologist, the social worker, the welfare rights worker, the residential care worker, the special teacher, the health visitor and the occupational therapist. Each cadre of professional concern develops its own cognitive style of appraising handicap with its in group jargon, house journals, specialist training and shared value systems (Thomas, 1982, p. 182).

One source has estimated that there may be as many as twenty-three different accredited helpers involved with people with disabilities (Brechin and Liddiard, 1981). This situation not only presents problems stemming from inter-disciplinary communication, and to some degree rivalry, but it also contributes to the process of mystification (Wilding, 1982). Each specialization tends to accrue to itself a code of practice which gives professional respectability and status to its work and its practitioners and distances these tasks and those involved in their execution from everyday life. As a result the lay person, because s/he does not feel able to act on his/her own, will become reliant on the 'specialist' skills of the expert. Any individual impairment is reinforced by a dependence on professionals. This process leads to an abdication of responsibility where interest, concern and skills are lost forever (Wilding, 1982). In addition, the professionalization of handicap enhances the social distance between the 'normal' community and people with disabilities by reassuring the former

that specialist help is available for those perceived as different. Consequently that difference is perpetuated.

The existence of all seven barriers taken together means that there is considerable pressure on individuals with impairments to accept a dependent role, and that it is problematic for them to seek integration (Hurst, 1984). How these obstacles effect the individuals in the Contact group is discussed below.

Environmental constraints become apparent as soon as the users leave the day centres. The importance of these constraints can be judged with reference to the last chapter and the fact that most Contact members do not leave the buildings without being accompanied by a member of staff. This is because each centre is located in a normal urban environment which is not geared to people with mobility difficulties. Excursions into the surrounding community are therefore a precarious experience both for the users and their helpers. Pushing wheelchairs is not as easy as it looks. It is extremely tiring and it demands a great deal of skill and concentration, particularly in a busy urban environment. This is partly due to the fact that many people who rely on wheelchairs are overweight, but more importantly because of the delicate and intricate manoeuvres that are necessary to negotiate uneven pavements, curbs, parked cars and busy roads.

Of the numerous examples I observed, one of the most memorable occurred at the Dortmund Square centre shortly after I joined the group as participant observer, when Joyce asked me to take her in a wheelchair to the central lending library. I was surprised by her insistence that she use a chair since it is something she is normally reluctant to do. The reason, however, became apparent as soon as we left the building. I had anticipated few problems since I had some experience of wheelchair pushing inside buildings, and the library is only ten or fifteen minutes' normal walking distance away from the centre. However, the journey there and back, not including the time spent in the library choosing books, took an hour and twenty minutes. This was due to the difficulties I encountered negotiating the uneven pavements in the city centre, moving up and down curb edges -there are eight vehicle access points and three main roads to cross on the way to the library building which means twenty-two separate manoeuvres -and the problems getting in and out of the library itself.

The library is on the first floor of a large Victorian structure and is only accessible via steps, apart from a side entrance normally reserved for service deliveries. On arrival at the building I had to leave Joyce sitting

outside while I went in to arrange for these doors to be opened. After about 5 minutes I returned with a security guard who let us in. A young caretaker apologized profusely for the general inaccessibility of the building and escorted us through what was obviously storage space. We had to ascend four steps to reach the lift to the first floor where the young man and I had to lift Joyce and the chair. The lift itself was designed for transporting goods and not operable by someone in a chair by themselves. The actual library was clearly not designed for people with impairments. There was barely enough room for someone in a chair to get through the doors, and the chairs and tables situated around the bookshelves were arranged in such a way as to render independent movement by a wheelchair occupant impossible. Although Joyce expressed some anger at this state of affairs she was evidently embarrassed by the situation. She assured me that she would return to the library as she enjoyed reading but never did during the study. What started out as an attempt by her to enjoy an activity most people take for granted ended in frustration and disappointment. What is also disturbing about this incident is that arguably one of the most important resources for people with limited mobility, namely, a public library, is so obviously outside their reach. But environmental barriers are not only problematic for people who are unable to walk without help.

Frequently when out with Andy, Jamie or Spike I was surprised by the problems they had when negotiating stairs or getting on or off buses, and the way in which these experiences exposed their vulnerability and transformed their personalities. When in the day centres all three strive to present a self-assured exterior, only rarely asking for assistance and often recounting exploits in the outside world which emphasize their relative independence. Outside, however, they are quiet, pensive and visibly concentrating on getting to their destination without mishap. This is particularly evident when they are in close proximity to large numbers of non-impaired people, such as in shopping centres, or when they are travelling by bus. For individuals with an unsteady gait being 'brushed past' by someone in a hurry can be a harrowing experience. It can often lead to them being knocked over which may result in broken limbs. Getting on and off buses is also a major problem because of the height of the step. It is frequently made worse by harassment by bus drivers and other passengers who seem impervious to these difficulties. None of the lads will travel by bus if there is standing room only. Andy's predicament on public transport is compounded by his epilepsy. Travelling by bus can sometimes induce an epileptic seizure which invariably means he is dispatched to the nearest hospital by well-meaning but ill-informed bus drivers or passengers. This occurred once during the study period.

Environmental considerations have a significant bearing on the activities of the entire Contact group. They are one of the principal concerns confronting users and staff when planning trips and outings. As well as the difficulties relating to transport and the number of helpers required, they limit where the group can actually go and what can be achieved when they get there. Sixteen users were permanently confined to wheelchairs and five often used them outside the centres, so a comparable number of helpers was needed for outings into the community. In a group discussion regarding the proposed annual outing (2 July 1987) I was struck, for example, by the lack of enthusiasm by a number of users for a proposed trip to a national leisure park. After a number of enquiries it became clear that several of the group held a view similar to that expressed by Curt immediately after the meeting was over.

'What's the point of me goin' somewhere like A. ..T. ..[leisure-park] where there's loads 'o rides an' stuff like that that I can't go on. I don't wanna go anywhere like that' cos it only meks you feel sick' cos you can't go on owt. I'd rather stop at 'ome.' +

I accompanied the group on four outings during participant observation. The first was on a trip to a country pub for lunch which included twenty-four users and ten helpers (10 July 1986). The second was to a newly opened shopping precinct in a nearby town and only consisted of eight group members and four staff (30 July 1986). The third visit was to a large national photographic exhibition (14 August 1986). Only seven users and four day centre personnel went on this occasion. My final excursion with Contact included six youngsters and three helpers and was to a large local pottery (16 September 1986). On each outing we encountered difficulties stemming from the physical environment.

Although access outside and inside the hotel on the first trip was generally good, the toilets were inaccessible to wheelchair users. At the shopping mall the only access from the car park, which was in the basement of the complex, for people unable to walk, was via the loading bay. Once inside, getting in and out of some of the shops and boutiques was almost impossible for individuals with mobility problems. Moreover, although the entire precinct spanned three storeys, there was only one lift which could only hold two wheelchair users and their helpers at once. Ambulatory shoppers, in contrast, are well catered for by escalators and staircases. Consequently much of the day seemed to be spent waiting to go from one floor to the next. The restaurants in this structure are all self-service and

again inaccessible to individuals confined to a chair. All the menus are located high above the self-service counters and are virtually unreadable to anyone with visual problems or reading difficulties.<sup>1</sup>

A similar situation confronted the group at the photographic exhibition which was also a multi-floored affair. Here there was no elevator, but a special chairlift attached to the main staircase which only held one individual at a time. It had to be operated by an appointed attendant. Again a lot of time was spent waiting around to use this device. While there were few difficulties with access at the pottery, because of the limited space in the workshop only two wheelchair-bound users and their helpers could go round it at once. This meant the group was split up and half the afternoon consisted of lounging about in the foyer doing nothing. On each of these occasions both users and the authorities concerned looked to senior staff to resolve these problems.

On the first outing helpers had to assist users from their chair into the toilets. Although this type of interaction is normal and accepted by both parties in the day centres, it was evident that the individuals concerned, particularly the users, were embarrassed because it occurred in a public place. In the shopping mall, the photographic exhibition and the pottery, senior staff occupied a central role, organizing lifts, meals and so on, in order to complete the visits inside the allotted time.<sup>2</sup> Indeed, although users were given every opportunity to go off on their own, they never ventured away from helpers.<sup>3</sup> While this may be partially due to their lack of experience in the community at large, the attitudes of the general public were almost certainly a contributing factor.

It was obvious on each of these outings that the able-bodied were not accustomed to interactions with the overtly physically impaired. At the restaurant, for example, the hotel waiting staff without exception addressed all their enquiries to the most visibly non-impaired on each table. And although some of the staff insisted that they make any enquiries to the individual concerned, it tended to continue throughout the meal. It was noticeable that some of the less visibly impaired, namely, Richard and Amy, were happy to speak for their contemporaries, but it was evident that several of the others were not used to such encounters and were clearly intimidated by the situation, hardly speaking during the entire lunch.

At both the shopping mall and the photographic exhibition I was conscious of the way non-impaired people stared at individuals in the group or turned away quickening their step to avoid eye contact. At each venue the officials concerned, the restaurant manager, the guides at the photographic

exhibition and at the pottery, directed all their conversation to the senior staff, virtually ignoring the users and the younger helpers. At the shopping mall the lift operator commented to me on the lack of facilities at the precinct, and almost as an afterthought asked my wheelchair-bound companions, Bruce and James, in a maternalistic tone which I considered would be inappropriate for an 8-year-old, if they were having 'nice time'. When we had moved away I asked them both if such situations bothered them. Bruce shrugged his shoulders and said nothing, James replied 'it doesn't bother me, you get used to it', and Bruce agreed.

It may be argued that more than one visibly impaired individual in a public place is bound to stimulate these or similar reactions from the able-bodied since such situations are unfortunately relatively rare, but the same type of behaviour occurred on each of the numerous occasions I was out with only one member of the group. For example, Bruce and I went to a large record shop to buy some records. It was clear by the way the other occupants of the store stared at us that someone in a wheelchair browsing through record sleeves was not an everyday event. When Bruce had selected what he wanted to buy I pushed him to the counter. Despite the fact that I stood immediately behind him and he was holding his proposed purchase, the shop assistant looked straight at me and asked, 'Doe he want this?' I replied that I did not know but it might be wise to ask him. She took the record jacket out of Bruce's outstretched hand and said in a louder than normal voice, 'Do you want this then?' Bruce's face flushed with embarrassment and he simply nodded. The girl took the disc from the shelves behind her and placed it in the sleeve, put it in a bag and stated the price without lifting her eyes from the till. She took Bruce's money, put it in the open drawer and passed the record and the change to me, over Bruce's head. I motioned for her to give it to my companion. Clearly distraught she did so and turned away, and we left the shop. Outside Bruce seemed unperturbed, by the incident and made no comment.

It is clear that he and the others in the group are used to this type of interaction. Data collected from a number of informal conversations with a cross-section of the group about this subject suggest that although the majority tend to gloss over such incidents many are still affected by them. As Roger commented,

'I used to get annoyed at first, but that sort of thing happens all the time, so you tend not to bother. It doesn't make any difference if you say anything anyway, some people just don't want to know.'

They've got their ideas and nothing'll change 'em'. I still get annoyed, but what's the point?' +

On two occasions during my time in the centres individuals in the Contact group were openly verbally abused by members of the general public. Both incidents took place at the Alf Morris centre in the summer when they were outside the building unaccompanied by staff. The first incident occurred when a number of youths shouted insults and obscenities relating to disability at several people sitting outside enjoying the sun and the second, when Sheila was crossing the yard after returning from the sandwich van. Three young men approached her and asked her if she was 'mental'. She said she was not, but they demanded proof. She became upset and began to cry and the youths began to laugh. When she moved away they started to make fun of the way she walked. She was deeply upset by this experience and spent the rest of the day in silence. Several of the Contact group could recall experiences when they had encountered overt hostility from the non-impaired because of their disabilities. In the formal interviews twelve respondents referred to such incidents. For example, in June 1986 Marilyn came home early from a holiday at a well-known seaside resort on the south coast because of the prejudice and negative attitudes she and her impaired friend Sharon had encountered in discos and pubs.<sup>4</sup>

Roger told me of an occasion when he was out with his mother in a local park and they were verbally abused by a gang of 'skinheads'. He said that when he and his mother retreated and she threatened to call the police the gang began to throw stones at them. Jamie stated that both his convictions for assault were caused by his retaliation after someone had made derogatory remarks about his impairment or called him names such as 'cripple', or 'spaz' (short for spastic) and this claim was verified by senior staff. The negative effects of these experiences are neutralized to some degree by sharing them with others in similar situations, namely, in conversations with other day centre users, and! or the psychological support provided by staff, whether it be through normal everyday interaction or specially arranged counselling sessions.

I was constantly reminded of the limited education many of the Contact users had received and the very real problems this created for subjective autonomy and integration into normal society. Their inability to read, for example, has already been mentioned in relation to relatively simple printed items such as menus, but it has clear implications in other areas, such as finding work, claiming benefits, housing and so on. And this in turn reinforces their dependence on others, particularly those in an 'official'

helping role. The extent of the educational barrier to integration is also evident in their frequent inability to handle money. Most of the Contact group are not responsible for their own financial affairs. Such matters are left to their parents. In fact for many handling money is a major problem. When I was asked by users to go to the shops for sandwiches or sweets, for example, some individuals would ask for an item costing less than 50 pence and give me all the coins they had, unsure if they had given me enough.

A memorable incident which illustrates this point occurred when the group was returning from an outing by coach and stopped at a service area for something to eat. While some of the group asked staff to get their food, others decided to get their own. Barry was one of the latter. He collected items valued at £2 75p. When he got to the cashier he gave her a one pound coin, which was all he had. It was plain from the expression on his face when the girl told him this was not enough that he had no idea of the cost. His subsequent silence during the rest of the journey indicated the level of embarrassment this incident caused him.

I noted in the last chapter that some effort is made by senior staff to encourage users to overcome these problems through education and that part of this policy involved a local college. After one visit it was clear that the facilities at this institution were inappropriate for individuals with the degree of impairment of many of the Contact group. I went to the college with Billy after he had been persuaded by Jayne and Benjamin to give the bridging scheme a try.<sup>5</sup> The college is a multi-storeyed building providing courses for 8,000 full-time and part-time students. There are a number of steps up to the main entrance, no classrooms below the first floor and only two small lifts. The ground floor accommodates student common rooms, a refectory, staff rooms and offices. The rooms in which the course was being taught were at the back of the building on the first floor. To get to the classes students had either to ascend a number of steps before entering the building or use a side entrance. Once inside they had to negotiate two flights of stairs or wait for the lift, cross a large foyer which was usually full of people and then pass through a series of narrow corridors. Although Billy had initially expressed some enthusiasm about going to college he was clearly shaken when he got there. When we got back to Alf Morris he said to Jayne,

'Why can't I do it 'ere? I don't really fancy it there.' +

His reasons for the change of attitude were never given.

As noted in Chapter Two the very existence of day centres is largely the result of the occupational barriers facing disabled people.<sup>6</sup> The idea that day centres are 'the last resting places' (Kent *et al.*, 1984) for people excluded from the world of work was clearly reflected in the practices of those who worked in the careers services during this study, such as Disability Resettlement Officers (DROs). Indeed, when planning the study I was told by one DRO that day centres were for the 'cabbages who wouldn't or couldn't fit in anywhere else'. Senior day centre staff were also aware of this attitude among this particular group of professionals, as the following makes clear.

'Unfortunately social services is seen as the last option, it's seen as the end of the road. When we started I thought we had a fine relationship with the careers service. But they don't seem to have the interest, we only hear from them when they want to make a referral.' \* - Jayne.

'DROs, I know they're there, but they don't come in unless they're making referrals. The only way people [users] have contact with them is if they take themselves off down to the job centre and ask to see one.' \* - Jackie

Any information relating to employment in the centres only came in via the users themselves, or through the efforts of the day centre personnel. Senior staff frequently circulated data relating to jobs among users. Jayne, for example, told the group of the plans for the new sheltered workshop three months before it actually opened. She received this information from the social services department, not the careers service. Most of the more able users, however, were put off working in this unit because 60 per cent of the workforce were to be mentally handicapped. One of the group did successfully apply for a job there but only stayed six weeks. The only individual to break through the occupational barrier, Marilyn, did so through her own volition, although she acknowledged her debt to the staff for providing motivation and practical assistance in the form of references and help with application forms.

Few of the Contact users seemed aware of the legal constraints on people with disabilities. From the data derived from informal conversations with users and staff it was evident that the majority leave their financial affairs to others, usually their parents. Other studies have noted that many similarly

impaired young adults are ignorant where their benefit entitlements are concerned (Anderson and Clarke, 1982). This did not apply to some of the moderately impaired members of the group. All expressed concern over what were, at the time, impending changes to the state welfare system. Joyce and Marilyn discussed in detail the implications for the latter in relation to loss of benefit and reassessment when she decided to look for work. Andy was especially critical of the assessment process for eligibility for mobility allowance, a benefit for which he does not qualify, despite his awkward gait and his difficulties on public transport. And Jamie is all too aware of the restrictions imposed on disabled people by state officials. Not only did he and his girlfriend have considerable difficulty finding out what assistance was available to them before the birth of their child, they were also forced to attend a 'case conference' where their competence as parents was critically assessed by doctors, social workers and others before they were allowed to keep it. It is inconceivable that this situation would have arisen if they had been non-impaired. With such considerations in mind it is not surprising that many of the Contact users experienced low self-esteem, limited motivation and a lack of confidence, synonymous with what Bowe termed the personal barrier to integration.

It was evident that of the six users who had become impaired at sixteen or after, at least five experienced adjustment difficulties. Apart from Billy whose problems have been documented in earlier chapters, Roger, Charles, Spike, Philip and Robert all ascribed the difficulties they encountered in their daily lives to their impairments. The only other individual disabled after sixteen, John, appeared to have adjusted fairly well to his paralysis although he did cite regaining the ability to walk as his only ambition. However, he rarely complained, was always cheerful and although he was not affiliated to any particular user clique, was relatively popular among the others. His successful adjustment may be explained by the fact that he had attended special schools since the age of eleven because of his inability to read, so in a sense he had already been socialized into a dependent role.

With regard to the others mentioned above, Roger's only goal in life had been to play the bass guitar in a rock 'n' roll band. The onset of his illness at 25 had undermined that completely since he was unable to stand up straight, had limited control over his hands and became tired very quickly. Before his impairment he had lived independently from his mother, had been a dedicated follower of fashion and had had a string of girlfriends. He had since returned to the parental home, although he did not get on with his stepfather, because he could no longer look after himself. He was also

aware that his condition, the cause and name of which were unknown, was degenerative. He was frequently prone to bouts of overt depression.

Charles suffered similar moods but his were exacerbated by his limited communicative abilities. His only aim was to make 'a complete recovery', despite the fact that his condition had remained constant for the past ten years. Prior to this he had led a completely normal life. He had had an apprenticeship with a well-established engineering firm and had looked forward to a prosperous and happy future until his motorcycle accident rendered him speechless and almost completely paralysed from the neck down.

Spike, on the other hand, had adjusted relatively well to his incapacities. The fact that his impairments were modest in comparison to others in the group and that his mother and stepfather were both impaired have probably helped. Within the Contact format he was seldom visibly depressed but often aggressive. Some senior staff within the centres ascribed this behaviour to his frustration because of his impairments. He had an unsteady gait, had difficulty controlling his hands, and spoke, as he put it, 'as if I'm always pissed'. He said, however, that he had 'enjoyed' violence before his accident, had collected militaria, practised the martial arts and joined the army as soon as he could. But although he was one of the most autonomous members of Contact he stopped going to college because he could not take the ridicule directed at him by the able-bodied students.

'People was treatin' me like a freak, not teachers, kids. Like when I walked down the corridor an' they walked past, cos' I 'av a funny way of walkin', they'd laugh an' some of 'em' d call me names as I was passin' , like freak. So I packed it in.' \*

Throughout the study Philip was experiencing severe marital difficulties which he clearly believed were the direct result of his impairment, although he said this was not the view his wife held.

'Well there's been quite a lot of argy bargy at home just recently. It's been a mixture of me wife wantin' me to do things around the 'ouse, an' sometimes I just think I can't do 'em. I just think they're beyond me. I put it down to me disability an' she puts it down to laziness. It's somethin' we've tried to get over, we were seein' a marriage guidance counsellor at one time. We're not seein' 'er now though. '7\*

Since 1984 Robert had relatively few problems integrating into the community, because it was something he did not attempt. His 'blindness' was the result of a car crash when he was 20, after which he regained some of his self-confidence and went out alone. But in 1984 he was knocked down by a car. He then rarely left the family home unaccompanied other than to go to the day centres. While there he did not move about without a 'guide'. He hardly ever involved himself in any activities, formal or otherwise, only spoke when spoken to, and admitted that he had little interest in anything since his accident.

With regard to the congenitally impaired users, the difficulties associated with the personal barriers to integration were most apparent in those who were relatively moderately impaired and able to walk. Those in what I termed subgroup B did not appear to manifest any adjustment problems. I ascribe this to a number of factors including the degree of their impairment and their socialization. Analysis of their individual biographies shows that they have on the whole been sheltered from what Bowe (1978) describes as the 'stress of confronting a harsh world' by their parents, their education and the day centres. Their protracted affective interdependence throughout has also provided them with an effective psychological defence mechanism against lowered self-perceptions which is mutually reinforcing on contact with the able-bodied world.

Because they were all wheelchair users their activity outside the day centres was extremely restricted. And since these devices act as signifiers of their dependence, when interactions between them and the non-impaired occurred, they were conducted upon firm foundations. There were none of the ambiguities and negotiations associated with encounters between the less visibly impaired and the normal. This accords with Goffman's (1968) account of the importance of what he termed 'stigma' symbols for minimizing uncertainty in confrontations between the impaired and the non-impaired. Furthermore, as there is a general resemblance between a wheelchair and a child's pushchair (Hurst, 1984), they were more likely to stimulate feelings in the non-impaired of overt pity or perceptions of the wheelchair users as eternal children, rather than outright rejection or hostility. The consequences, therefore, are potentially less psychologically destructive, particularly if such perceptions are all the individuals concerned have known. It is significant that none of the people in subgroup B reported having experienced first-hand the extreme negative attitudes toward the disabled described by other Contact members.

Those in what I termed subgroup C hardly ever left the day centres without a member of staff and when they did their behaviour was decidedly subdued, and in specific cases withdrawn. For those such as Gavin, who was confined to a wheelchair, this was probably due to environmental limitations and the severity of his illness, but for the remainder it was due to a life-long experience of impairment and negative discrimination. Several had been subject to patent animosity by the non-impaired. For example, Karen, Barry, Nancy, Richard and Wendy each had distinctly unpleasant memories of ordinary schools which had a profound effect on their self-esteem. Barry spent- much of his formal interview telling me how he was 'picked on' when he went out. Karen felt that she was an object of ridicule in her neighbourhood and Wendy frequently spoke of how she was bullied in the children's home where she lived. They all, apart from Nancy, complained of being stared at when they were out in the street. And since their impairments were overt, 'passing' as normal was out of the question. Consequently each, to varying degrees, had opted for withdrawal as a safeguard against further emotional damage.

Withdrawal was not the general strategy adopted by the remaining members of the Contact group -Joyce, Andy, Jamie, Molly, Matthew and Marilyn. But passing was also out of the question since their impairments were clearly overt. Despite their relative independence, both inside and outside the day centres, integration into able-bodied society was nonetheless difficult and the ensuing psychological consequences equally debilitating. While they identified with the norms and values of the non-impaired community, many of their attempts to integrate into it had met with failure and disappointment. As noted above, all have experienced some rejection and hostility from the non-impaired. The cumulative effects of these experiences have had a significant impact on the individual consciousness of each. It found expression in their attempts to distance themselves from others within the Contact group who appeared to accept their dependent status willingly, and their general ambivalence toward day services. For example Molly told me in a discussion about friends,

'I wouldn't be seen dead with some of this lot in 'ere outside. They're pathetic.'\*

As his formal interview drew to a close Andy told me

'I'm not like most of 'em in 'ere you know. I only come so's I can get a job wi' the social services.'\*

He has been a Contact member for the past six years. Matthew stated,

'I don't know why I come 'ere really 'cos I'm not really disabled, not like some of 'em in 'ere. When me uncles ask me why I come, I tell 'em cos' I 'ave to cos' me doctor says so.' \*

There was also a very real belief by some of these individuals that the experience of impairment was worse for them than it was for others in Contact, particularly those in wheelchairs.

'I think some of the members in the group, them in wheelchairs, I think they've been brought up with, I don't know how to explain it. ... They've been brought up as though their handicap's not a bad thing to live with. They've never actually been in the street and had the mickey taken out of them. They've never been in the street and been made fun of. If I walk down the street people will notice. We walkers have alot more to put up with because as soon as people see someone in a wheelchair they think "Oh that person is handicapped". They don't understand if you've got a walkin' problem.'\* -Marilyn.

The emotional consequences of these perceptions were manifest in occasional moodiness, aggression and depression. One of the most memorable examples of the latter occurred shortly after I had joined the group on a full-time basis (14 July 1986) when Joyce arrived in a particularly depressed state. She spoke to no one unless they addressed her first and looked as though she might burst into tears at the minimum provocation. I found out from her best friend Marilyn that she was upset because it was her birthday. Later that day I began a conversation with her and after her mood appeared to improve I told her I knew it was her birthday and that I found it difficult to understand why she was so unhappy about it since she was still young. She replied,

'You might do Colin if you were disabled. ...What have I got to celebrate, what have I got to look forward to? Another year in this place? I don't want to be stuck here for the rest of my life, and end up like some o' them down there [elderly users].' +

She was only 25 years old.

The fact that many of the users were directed into the day centres by professionals provides evidence of the professional barrier to integration, if only because the centres are clearly discriminatory, although such arguments should be offset against professional awareness of the extreme social isolation many young disabled people experience in the community at large. However, apart from the initial referral, there was little involvement by professionals once individuals were in. This was explained by senior staff with the claim that most agencies see the day centres as 'dumping grounds' for people with nowhere else to go. Throughout the first nine months' participant observation there was no evidence to contradict this view. But in March 1987 a social worker for physically disabled children began to visit the group on a regular basis at Jackie's request, normally once a fortnight. In July 1987 an occupational therapist was appointed by the Social Services Department whose responsibilities included the Contact group. Up to then the only involvement users had with these workers was either direct or through the day centre staff.

Only a minority of the users appeared to have definite views with regard to professionals. Some, such as Paul, for example, expressed antipathy toward those who work in the careers services for directing them into the day centres rather than finding them work. Billy and Nancy were particularly critical of doctors for their failure to provide adequate information regarding their impairments.<sup>8</sup> Several of the group, particularly those with acquired impairments, appeared to have a high regard for the medical profession, though they viewed other professionals such as social workers with polite indifference and occasional disdain.

Many users had little knowledge of what services were available and some were clearly intimidated by officialdom. During this study, their own and their families' involvement with other agencies was usually mediated through one or other of the senior day centre personnel. While it may be argued that their reliance on staff in this way merely sidesteps the central issue, since they are still dependent on a group of formal helpers, it is generally accepted that many people's needs go unmet because they find dealing with professionals and professional agencies difficult (Glendinning, 1986). It is also important to note that any involvement by day centre personnel in this regard was invariably instigated at the users' request.

This section has focused on the seven major environmental and social barriers to the integration of people with impairments into 'normal' society, architectural, attitudinal, educational, occupational, legal, personal and professional, and the consequences of each in relation to the Contact

users. The evidence shows that architectural and/or environmental considerations are of primary importance in (if not the most important factor) restricting users' movements outside the centres. This applies to both individuals, and to the Contact group as a whole. This is applicable not only to the more severely impaired members of the group who are unable to walk, and rarely leave the units without an approved helper, but also to those who can. The examples provided show that as a result of the physical difficulties encountered by users outside the day centres, the behaviour patterns of the most overtly autonomous members of the group were altered and that their vulnerability was exposed. Besides undermining individual self-confidence and esteem, this helps to perpetuate the essentially negative attitudes associated with disability among the able-bodied, particularly those which suggest that all the impaired are dependent and helpless. It was evident that the most common attitudes encountered by users during initial interactions with the non-impaired were consistent with this view, encompassing covert pity and the 'does he take sugar?' syndrome and rarely passing beyond 'fictional acceptance'. It was also apparent that overt rejection and discrimination are not uncommon. The extent of the educational barrier facing many Contact members was reflected by their illiteracy and inability to handle relatively small sums of money. By focusing on a visit to a local college of further education I demonstrated the difficulties facing disabled people who try to overcome these limitations in an 'ordinary' educational environment. With regard to occupational obstacles, I suggested that the very existence of the day centres is evidence of the lack of occupational opportunities available to the individuals in the Contact group and that the lack of involvement by the careers service in this system underlines this view. Several Contact users have confronted the complexities of claiming procedures and the legal constraints imposed upon people with impairments and have found the experience highly stressful. The most extreme example was Jamie's and his girlfriend's confrontation with state bureaucracy in relation to their parenthood.

With regard to the personal barrier to integration, the data suggest this is less of a problem for those born with significant impairments, who have been socialized into accepting their dependent status and have been sheltered to some degree from able-bodied society, than for the majority of Contact users. Those with acquired disabilities all experienced problems of daily living which resulted in lowered perceptions of their own worth as human beings. The remaining congenitally impaired members of the group, particularly those who were 'moderately' disabled and able to walk, appeared to experience similar feelings. But while some reacted to these

emotions with varying degrees of withdrawal, others expressed ambivalence toward the day centres, and animosity toward their impaired contemporaries who appeared to have accepted their disabled identity.

The evidence shows that professional involvement in the day centres during participant observation was limited and that apart from an almost unanimous antipathy toward the careers service, users' views on this subject were inconclusive. This was probably due to the fact that most Contact members and or their families' dealings with other agencies were usually conducted at their own request, through the day centre personnel. In sum, this section has drawn attention to some of the material and social problems encountered by the Contact users in the community at large and has shown how these experiences affect their behaviour and reinforce dependence. The following section focuses on their leisure and social activities outside the day centres.

### Leisure / Social Activities and the Contact Group

It has become increasingly apparent in recent years that the sociology of leisure is a relatively neglected area. This may be due to the general view that leisure is linked to the social and ideological superstructure of society rather than the economic base. Cultural norms and values socialize us into the belief that work is good and idleness reprehensible (Parker, 1975). We perceive leisure as a marginal period of recreational activity which can only be legitimately enjoyed in conjunction with work. Consequently the long-term unemployed, who ought to be able to adjust to a life of leisure, usually find it difficult (Fagin and Little, 1984). Although people with impairments have consistently been excluded from the world of work it is only within the last decade or so, since unemployment in Britain reached unprecedented levels, that serious consideration has been given to the problem of giving meaning to a life without paid employment.

The phrase 'significant living without work' entered the vocabulary of professionals in the field of disability and rehabilitation after the publication of the Warnock report in 1978. In keeping with the general shift toward self-help the report stated,

We believe that the secret of significant living without work may lie in4 handicapped people doing far more to support each other, and also in giving support to people who are lonely and vulnerable (quoted in Kent and Massie, 1981, p. 33).

This suggestion fails to take stock of the very real problems facing people with disabilities and is unrealistic since most individuals with impairments capable of voluntary work will almost certainly be seeking employment in the open market.

Kent and Massie further report that there have been a number of proposed solutions to this problem, such as quasi-legal substitutes for paid employment, work-type activities undertaken for people without a proper job, and the instigation of some form of training for unemployment. There are, however, distinct dangers in educating people, particularly those with impairments, for unemployment. They suggest that the most obvious is that professionals will decide when a child is young that s/he is unsuitable for work. Her/his education will then reflect this view resulting in a self-fulfilling prophecy, which produces a downward spiral in professionals' expectations about the potential for achievement of disabled people. These authors rightly point out that if significant living without work *is* to become a real option in the future and not merely an elaborate way of disguising a life without purpose lived in comparative poverty then it must not be a lifestyle reserved exclusively for the disabled. From what is termed an 'interactionist standpoint' Coe summarizes the situation well.

Only when the able-bodied cease to look for employment will I stop advocating the need for the handicapped to obtain satisfactory paid employment (Coe, 1979, quoted in Hurst, 1984, p. 216).

At present individuals with impairments facing a lifestyle of long-term unemployment also face a life of relative poverty which often adds to any problems of low motivation, lowered self-esteem, and social isolation. This is generally reflected in the pattern of leisure and social activities they pursue.

There are a number of studies which show how non-impaired young adults spend their leisure time. Two notable examples which involve large representative samples are the National Child Development Survey of 16-year-olds (NCDS) and the Isle of Wight study of 14-year-olds (Rutter, 1979). Both confirm that in the mid-teens the amount of peer group contact outside school is very high, both in terms of the number of times peers are seen, and in the number of friends seen in an average week. In the Isle of Wight survey, less than 10 per cent of the sample were reported to have had no peer contact in the previous week, while over half had three or more

contacts. Although less than 30 per cent claimed to be a member of a gang, almost half were members of clubs, and at least a quarter had visited a club at least twice in the previous week. Over 70 per cent said they had a special friend and three-quarters of these were on visiting terms with these friends. Few of the sample went out regularly with their parents, over one-third never went out with them at all and only 10 per cent once a week (reported in Anderson and Clarke, 1982).

With regard to the use of leisure, the Rutter study showed that watching television was a very common way of spending time. This underlines Parker's assertion that this is the leisure pursuit which takes up more time for more people than any other. Reading was another common activity. Less than a quarter of the sample said they rarely read books. This was also a popular leisure activity among the respondents in the Isle of Wight study. Going to the cinema was also a regular pastime, nearly half averaging at least once a month while a quarter went two or more times. Engaging in outdoor activities and sports were also popular activities, nearly 50 per cent of the respondents in the NCDS survey playing 'often' and one-third 'sometimes'. It was reported that very few of the young people said that they felt lonely 'often' while 60 per cent said that they never felt lonely.

There are relatively few studies of how young people with impairments spend their leisure time. Three important exceptions are Dorner's (1976) analysis of teenagers with spina bifida, Rowe's (1973) study of young people with cerebral palsy, aged 18-30, and Anderson and Clarke's (1982) study. Rowe found that nearly 20 per cent of his sample had never been out of the house at all other than to go to their Adult Training Centre (ATC) in the preceding week. He found that 60 per cent of his respondents would have liked to go out more. They cited transport and access difficulties to places of entertainment as the main causes of their confinement. Rowe stated that those who could drive were emphatic about the difference this had made to their lives. In general, watching television and listening to music were the most common activities named. Reading was not popular. A quarter said they found reading difficult. Over half of the Rowe sample claimed to have a hobby but this included listening to records which is often a solitary passive activity.

The Dorner survey found that most of the teenagers interviewed had friends although these relationships were limited to school or college. Those in special schools saw no friends at all in the evenings, on weekends, or during the school holidays. Social isolation in this study was

closely related to mobility difficulties and virtually all those affected were perceived as socially isolated.

Anderson and Clarke compared the leisure and social activities of 33 able-bodied and 119 physically impaired adolescents between the ages of 14 and 18. Of the physically impaired respondents, 89 had cerebral palsy and the remainder spina bifida. Sixty-three were, or had been in ordinary schools and the rest in special education. In general they found that the youngsters with disabilities spent far more time engaged in passive solitary activities such as watching television or listening to music than their able-bodied peers. Few had well-established hobbies with which to occupy themselves' constructively'. Reading was less prevalent among the impaired than the non-impaired, which the authors attribute to the difference in literacy skills between the two groups. In comparison to the non-impaired, a large number of the youngsters with disabilities belonged to a club. But most were members of clubs specifically for the disabled and over a third of these were school-based and closed in the holidays. The authors contend that this type of club membership is due to the impaired individual's need to compensate for their lack of peer contact. The benefits of club membership in relation to integration into the community were therefore limited.

They found that although those with a background in ordinary education were a relatively mobile group, they had a very limited social life when compared with the non-impaired. For example, a third said they hardly ever saw friends outside school. This applied to only 10 per cent of the able-bodied. They were also much more likely to go out with siblings or parents than were the latter. This also applied to those from special schools. Nearly three-quarters of the sample with impairments normally went out with one or more members of their family, while the non-impaired almost always went out with peers. Of those in special schools 60 per cent never socialized with their friends outside school, over half had never been to a friend's home and only a quarter had made such a visit in the last month. The researchers concluded that the overall degree of handicap, especially related to mobility, was closely linked to the amount of social contact the teenagers had. The more mildly handicapped led the more active social lives.

The difficulties experienced by those in special schools were said to be compounded by two other factors, First, the majority only had friends who were themselves impaired. Therefore on both sides of the relationship there were difficulties in making social contact. And secondly, those from

ordinary schools, impaired or otherwise, had friends living within walking or wheeling distance from home. It was evident, however, that fewer of the impaired from normal schools, in relation to their non-impaired peers, had a particular friend. These writers contend that apart from mobility, no particular impairment seemed to influence peer relationships although those with speech difficulties tended to be more solitary with fewer peer contacts. They concluded that the majority of the impaired teenagers suffered high levels of social isolation (Anderson and Clarke, 1982).

A more recent analysis which compared the lifestyles of impaired and non-impaired young adults, was that conducted by the Paediatric Research Unit at the Royal and Devon Hospital between 1983 and 1985 (Brimblecomb *et al.*, 1985). This research focuses on the lives of 511 young adults aged between 16 and 25,385 of whom had been labelled as handicapped or disabled because they had one or more physiological, sensory and in some cases, cognitive disorders. The study demonstrated that in this particular age group the non-impaired are three times more likely to be living independently from their parents, employed, and married, than their impaired contemporaries. They also found that social isolation was widespread among the latter. Although these researchers did not cover leisure activities in detail they showed that three times as many handicapped people as non-handicapped never went out socially in an average week and almost double the percentage of cases (52 per cent as opposed to 28 per cent) went out on two days or less. Only 3 per cent of the able-bodied respondents never went out with friends. Brimblecomb and his colleagues found that the impaired young adults sampled were less likely to be involved in 'normal' social activities, such as going to the pub, generally associated with people in their age group. As a result many felt there was a 'shortfall' in one or more areas of their social lives. These included lack of friends, social facilities and transport. As a result they had a poor self-image. In contrast to the non-impaired twice as many of the disabled respondents said,

that they often felt lonely, miserable or that life was not worth living, three times as many of them were not able to say they often felt happy (Brimblecomb *et al.*, 1985, p. 63).

It is important to note that similar experiences are also encountered by other socially disadvantaged groups in the same age range excluded from the world of work. Willis' (1985) recent study of the social condition of young people in Wolverhampton aged 16 to 24 found that social isolation was invariably the outcome of long-term unemployment. Willis shows that

unemployed young people are less geographically mobile than their employed contemporaries, though this was obviously not due to subjective impairments but rather to a lack of money. Over half of those interviewed said that they could not afford to go out. The study shows that their leisure and social activities were radically different from those of their employed peers, being far less involved with commercial forms such as cinemas and discos, for example, and much less structured. The author concluded that there is an overall tendency for the long-term unemployed to be less active and more housebound.

The most common activities among this group were watching television and listening to music, and they were much more socially isolated than their employed contemporaries. Willis shows that for those out of work 'even courtship loses some of its social centrality'. He concludes that in many ways the young unemployed have been thrust into a new social condition of 'suspended animation' between school and work since many of the old traditions have frozen or broken down. Instead they experience a period of relative poverty and dependence on the state. This new social condition is characterized, Willis says, by some or all of the following: alienation (which he defines as feelings of separation from society, and suspicion of its main agencies and centres of power), depression and pessimism about the future. Whether or not this is a new phenomenon, or whether it will be a permanent feature of British society in relation to the young non-impaired, is open to speculation, particularly in view of the 'greying' population and the shortage of labour that this will inevitably cause in the not too distant future. It is, however, similar to that experienced by the young people with impairments in the studies already discussed and most if not all of the individuals in the Contact group.

The data provided by the formal interviews clearly show that the majority of users had few hobbies, spent most of their leisure time in the family home, were reliant on their families for social activity and had little or no contact with their able-bodied peers (see Table 17). Fourteen of the sample said that they had no hobbies whatsoever other than watching television or listening to music. Matthew, Paul and Gavin collected stamps, and the latter said he spent most of his time at home playing with his computer. Karen and Angela cited needlework as their primary leisure activity but while Karen enjoyed sewing and embroidery, Angela confessed that she probably would not bother if it was not for her grandmother who 'was always goin' on' about her doing something 'useful' .'\* Jamie and Bruce said that they were keen football supporters. Both followed a specific team, but neither regularly went to matches, although they had been to important

games in the past with members of their respective families. Four of the sample, Joyce, Andy, Sheila and Marilyn, said that they were avid readers. The three girls preferred biographies and romantic novels while Andy opted for science fiction and horror stories. Joyce and Marilyn also cited cookery as one of their favourite pastimes. In conjunction with her mother and sister, Molly bred, trained, and showed pedigree dogs, and Richard said that his main interest outside the day centres was looking after a pony owned by a friend of his mother's. Roger was the only respondent who played a musical instrument but admitted his interest had waned because he could no longer play as well as he once did. When he was not at residential college, Tony was a keen radio ham and a member of a local radio club. This did not, however, involve face-to-face contact or his leaving the family home.

Only three of those sampled were members of clubs not directly associated in some way with disability. Nancy was a member of a Bingo club, which she says she was only allowed to attend with her father, and Jamie and Spike were members of local working men's social clubs. Many of the respondents, fourteen in all, regularly went to clubs for the disabled. Norman, James, Curt and Elizabeth occasionally attended a local sports centre on Tuesday evenings when the facilities were reserved exclusively for people with disabilities.<sup>9</sup> But while Elizabeth went because she enjoyed weight training, the others said that as far as they were concerned it was a site for social activity rather than keeping fit.

'I only go for the bar an' the food, I'm not interested in sport or owt' like that.'\* -Curt

This club has also been regularly used by at least six others in the past but none of them were attending during the study. Twelve of the respondents attended one or both of the local Physically Handicapped and Able-Bodied (PHAB) clubs on a regular basis. The clubs met each week. One was located in the local special school where most of the group were educated and the other at the Alf Morris day centre. This was a temporary location in the case of the latter since the property normally used by this club was being renovated. Both were closed in the school holidays.

Margaret, Norman, Gavin, James and Millie went to both almost weekly. The remainder only used the club located at the Alf Morris complex. Angela was a

*Table 17 Leisure and Social Activities of the Contact Users Outside the Day Centres*

regular user of these facilities until March 1987, but was subsequently stopped by her parents because she had a number of severe epileptic seizures while there. Others in Contact including Paul, Barry, Henry, Wendy and Clive, also expressed an interest in going to one of these clubs. According to Wendy and Clive, the only reason they did not go there already was that they were not able to get transport. Both lived in residential institutions. Surprisingly even Matthew and Roger said that they had considered going along to see what the clubs were like simply 'to get out of the house more'. However, the other moderately impaired users sampled were extremely critical of these organizations. All said that they had attended at some stage (invariably when they first heard about them, shortly after joining Contact) but said that despite their name, Physically Handicapped and Able-Bodied, they were mostly frequented by people with impairments and that the only non-impaired people there were helpers. Moreover, the age span of the membership included small children and 'old people', and the clubs closed at 9.30 p.m.

'It's just like comin' to a day centre only at night. If I come 'ere durin' the day I don't want to come back an' see the same people at night.' \* - Marilyn

'It's dickie that place man. They're all dickie that go there you wouldn't catch me goin' there.'\* -Billy

Two of the adventitiously impaired respondents, Philip and Robert, were regular visitors to a self-help group for people with head injuries called 'Headway' which met once a month at the Dortmund Square day centre. Both said that they had found going to this club helpful for coming to terms with their impairments.

It is clear that without these organizations the social lives of most of the sample would have been even bleaker. Indeed, ten of the respondents said that they never went out at all and one girl, Karen, said that her only excursion out of the family home other than to the day centres was to church. Parental influence cannot be ignored here since her father was a lay preacher. Two went only once a month and two once every fortnight. The remainder averaged once or twice a week, apart from Marilyn whose tally was three or four, and Andy who said he went out every night, albeit five or six of these were trips to his mother's house.

For those who went out more than once during the week, this usually meant a visit to the pub or social club in the evening, usually Fridays or

Saturdays, and at Sunday lunchtime. Only one respondent, Paul, said that he 'sometimes' went to the cinema. This alternated, he said, with going out for a meal. Joyce, Marilyn and Robert also cited eating out as one of their social activities. But Marilyn was the only member of the group who regularly-went to discos or night clubs. Only seven of those interviewed said that they regularly went out without family and all were ambulatory. Joyce, Andy, Marilyn, Richard and Spike said that they hardly ever went out with kin, although Richard's only social activity outside the home involved babysitting at a friend's house on Saturday nights. Jamie and Molly both said that they went out with members of their respective families as well as by themselves. The rest only went out with siblings or parents or, in Clive's case, with people from the residential home where he lived. Whether or not the majority of users would have chosen these locations for socializing is open to speculation, since the data clearly show that they were normally only 'taken out' by someone else.

Although the quality of their social lives was a bone of contention for all the users interviewed, it was clearly more important to some than others. The individuals in subgroup B, for example, were apparently less dissatisfied with their social situation than the rest of the group. They were all regular visitors to one or more of the clubs for the disabled, and were less critical of them than others in Contact. This may be explained with reference to the factors discussed earlier, particularly their limited mobility.

However, the individuals in subgroup C felt that they should be going out more. Wendy put it this way,

'A young girl like me should be goin' out. My life's just wastin' away. I never go anywhere. I should be goin' out like the others in the house [children's home].'

Wendy's lack of social activity cannot be attributed to mobility problems since, although she had a limp, she had little obvious difficulty walking. Moreover, as she lived in a children's home, where others in the house did go out, her social isolation may only be explained with reference to social rejection by the non-impaired and/or psychological factors, or the personal barrier to integration. Indeed, she had no ready explanation for this phenomenon unlike others in the sample. Paul, Karen, Barry, Henry and Nancy, for example, all cited their parents' over-protectiveness as the principal reason for their lack of social activity outside the parental home.

'I think I should 'ave more freedom than what I've got, I'm 20 years old. If I ask to go out me dad says to me, "no we daren't let you go out in case you' ave an accident an' end up in 'ospital". I mean it gets above a joke I never go anywhere. I might as well be 50. It's not really fair is it?\*' -Nancy

This situation was particularly disturbing for someone like Karen where rigid parental controls were not extended to her younger sister.

'I'd like to go out more, but me mum doesn't let me, she says I'll get poorly. It's not fair 'cos me sister goes out an' she's younger than me. She goes out but I can't.' \* -Karen

None of the interviewees, apart from Joyce and Marilyn, could name current friends their own age, who were not involved in the day centres or clubs for the disabled, either as users or helpers. With regard to able-bodied friends Joyce maintained that she had a girl friend she saw 'quite regularly' whom she met at college and Marilyn said she had several friends in the pubs/discos she used. Andy, Jamie, Matthew and Spike all said that they 'knew' people who were not disabled, but would not consider them friends.

Apart from Jamie and Philip, only three of the sample, Sheila, Norman and Angela, said that they had a regular relationship with a member of the opposite sex. Sheila said she was 'going out' with an able-bodied helper from one of the PHAB clubs 10 and Norman and Angela were officially engaged.

The majority of the respondents had few plans or ambitions for the future and many seemed to view their prospects with obvious pessimism. As noted above, those respondents who acquired impairments after the age of 16 only had ambitions concerning their lost abilities. Although fifteen of the others wanted a job; they all saw this prospect as highly unlikely. Jamie said that he would like to set up his own jewellery business. A further six nominated getting a girl/boyfriend. The rest said that they had no ambitions because they felt there was little point.

'If you don't have ambitions you don't get disappointed. I don't like thinking too far ahead because the future frightens me. I don't like thinking I'm gonna do this or that cos' nearly always I've been disappointed. The things I want, friends, family, someone to love me, seem miles away.'\* - Joyce

Although at various points during the formal interviews and during participant observation many of the user respondents had expressed a desire to leave the day centres, in response to the question 'are you likely to be leaving the day centres in the foreseeable future?' nineteen said it was unlikely. While some seemed resigned to this prospect without undue visible concern, others were clearly worried by it.

'I might have a couple of quick breaks if I get fed up, but I can't see it really [leaving the day centres]. I can't see me leavin' it altogether. It's better than nothin'.' \* - Curt

'It's alright but, I thought to myself, our group is for the 16-to-30-year-olds. There's some that goes on 'til you're 40 an' there's some that goes up to 80, an' if I go on 'til I'm 30 somebody'll say "you've got to go on to the next one". I don't want to end me days in 'ere.'\* -Paul

Of the remainder, only Jamie, Molly and Marilyn were sure that their attendance would cease, Jamie because of his family commitments, Molly because she was simply 'fed up with the place' and Marilyn because at the time of her interview she had applied for the job which she subsequently got. The rest could not give a definite response.

This section has looked at how the users in the Contact group utilized their time when not in the day centres. It identified the level of social isolation many of them experienced in the domestic sphere and underlined the importance of these units as a forum for social interaction. It began with an appraisal of recent theoretical analyses of leisure and concluded that how we perceive leisure is culturally determined, but that generally it is viewed as a marginal activity which can only be enjoyed in conjunction with work. Hence the long-term unemployed experience considerable difficulty adjusting to a life of permanent idleness. With regard to people with disabilities, following Kent and Massie (1981), I noted the added dangers inherent in the notion of 'significant living without work', namely, labelling by professionals, separation from the rest of society, relative poverty, and lowered self-esteem.

Empirical studies of how non-impaired teenagers spend their free time show that generally there is a high level of peer group contact and that although passive activities are not uncommon, social activity usually involves commercial forms and participation with others. The data also

demonstrated that during the mid-teens most individuals are relatively autonomous from the family in relation to their use of leisure time and social isolation is unusual. In contrast, studies of young adults with impairments show a high level of dissatisfaction regarding their social lives. Outside formal institutions, teenagers with disabilities have few peer contacts, are more likely to be involved in solitary passive activities only and are almost entirely dependent on the family for social activity. As a result they experience extreme loneliness. The data show that there is a correlation between limited mobility and social isolation and that between 16 and 25 years, non-impaired young people are three times more likely to be living outside the family home, employed, and married than their impaired contemporaries. It was also noted that the experience of unemployment is in some ways similar for both non-impaired and impaired young people with regard to their use of leisure time, but that for the latter it is likely to be a permanent way of life.

The empirical evidence collected during the present study regarding leisure and social activities of the majority of the Contact group largely corresponds with the findings outlined above. Relatively few of the respondents had specific hobbies or interests with which to occupy their time. And apart from the day centres and clubs for the disabled, most users had few if any contact with peers, impaired or non-impaired. Apart from these activities, almost a third of the respondents had no social contact outside the parental home whatsoever and over three-quarters of the sample never went out without a member of their family or guardian. Although there was a degree of dissatisfaction among all user respondents with regard their social lives, it was most acute among the more moderately impaired respondents. Notwithstanding that their only social activity revolved around specialist clubs and/or their respective families, those individuals with severely restricted mobility appeared less dissatisfied than the others interviewed. While not applicable to all, several of those who were able to walk ascribed their lack of social activity to parental control. Only two of the sample had non-impaired friends, and only five claimed to have permanent relations with the opposite sex. [n this instance, therefore, it is not necessarily the more mildly physically impaired who lead the more active social lives.

The majority of the respondents had few plans or ambitions and viewed their prospects with an unmistakable air of pessimism. Although several were evidently deeply unhappy about the situation, most did not expect to leave the day centres in the foreseeable future. For the majority, due to circumstances largely beyond their control, the day centre system and the

Contact group in particular represented the only real opportunity for social activity outside the family home.

## Conclusion

In this chapter I have examined the problems encountered by the Contact users outside the day centres. The first section looked at the seven major environmental and social barriers to integration which confront people with disabilities generally, and illustrated the extent to which the Contact users were disadvantaged in these areas. The evidence reaffirms the general view that environmental factors are the major barrier to normative integration. They affected not only individuals in Contact, but also the activities of the group as a whole. I then noted the awkwardness and unease which proliferates in social interactions between Contact users and members of the general public outside the day centres, and in addition, that overt rejection and hostility were not uncommon. This section brought to light the very real disadvantages Contact members experience as a result of their inadequate education. The most telling indictment of that education is that many individuals in the group cannot handle relatively small sums of money. Although day centre attendance itself is verification of the lack of employment opportunities open to Contact members, I drew attention to the dearth of involvement by the careers service in this system. It was shown that the excesses of the legal and bureaucratic constraints on people with disabilities were most acutely felt by the more autonomous members of the group.

In terms of self-perception, it was evident that the cumulative effects of these phenomena has had unmistakable consequences for all Contact users, although the experience of impairment was apparently less problematic for some than it was for others. Although those with acquired 'severe' impairments appeared to experience problems of adjustment, the data suggest that among the congenitally impaired integration was relatively more emotionally disturbing for individuals with 'moderate' physical impairments than it was for those with severe conditions. This underlines the pressure on individuals to adopt a dependent status and the general view that it is easier to accept dependency rather than reject it. This section concluded with reference to the professional barrier to integration and how day centre staff helped to circumvent this particular problem.

The consequences of these considerations in relation to the users' leisure and social activities was demonstrated in the second part of the chapter.

The majority of the group spent most of their time outside the centres, engaged in solitary passive activities, had little or no peer contact and were almost totally dependent on their respective families for social activity. Consequently there was a disturbingly high level of social isolation among most Contact users. The negative effects of this isolation were mitigated to a degree for some by their use of the specialist clubs for the disabled associated with the day centre system. It was apparent that while there was a definite discontent among all the sample concerning their social lives, it was less conspicuous among those individuals who appeared to have accepted their dependent status and attended these clubs regularly. But without exception dissatisfaction concerning social activities was highest among the less severely impaired members of the group.

In the final analysis this chapter has shown how environmental and social factors in the wider community impose constraints on the activities of all the users sampled, and in turn reinforce disadvantage. The data also show how day centre attendance helps to alleviate some of the negative effects of that disadvantage as it brings users into easy contact with a range of resources not readily accessible for people with mobility problems. In addition, by focusing on the excessive levels of social isolation experienced by the majority of the Contact group and their desperate need for social interaction, this chapter underpins the importance of these units as a forum for social activity. In view of these considerations it is highly probable that many of the users will, to varying degrees, become almost exclusively dependent on both day centre staff and the system as a whole. In the majority of cases this is an unwanted dependence which can only have a debilitating effect on their already limited self-confidence and self-esteem. Although in the present social and political climate it is debatable whether or not this disturbing situation can be avoided, one possible solution is discussed in the final chapter.

## Notes

- 1 This state of affairs is even more alarming considering the recent construction of this shopping complex. It was officially opened in 1983.
- 2 Users had to be back at the day centres at 3.30 p.m. for their transport home.
- 3 None of the more independent members of the Contact group went on the last three outings discussed.

- 4 Sharon was only marginally impaired with a slight limp. She only attended special school at the primary level, had a job in a bank and owned her own car. She has never been a day centre user.
- 5 I was recruited to provide the physical support Billy needed when walking. When he visited the college he was still relatively ambulatory and did not want to go in a wheelchair.
- 6 The extent of the occupational barrier is patently manifest in the work experience of the Contact users discussed in Chapter Five.
- 7 Philip's marriage broke up shortly after the study period finished. He subsequently went to live with his parents.
- 8 During the study Nancy was having treatment at an out-patient clinic at a local hospital for high blood pressure. She said she had never been told what caused this condition or what consequences it might have for her in the future.
- 9 This is the same sports centre used by the Contact group for swimming and weight training.
- 10 This was later confirmed when he accompanied Sheila to the Christmas lunch. However, although not physically impaired it later became apparent that Sheila's boyfriend had attended a special school for children with learning difficulties.