

## **Chapter 5 (In 'Cabbage Syndrome': The social construction of dependence, Colin Barnes (1990) The Falmer Press, pp. 90-126)**

### The Contact Users

From the evidence presented in the last chapter it is clear that the Contact group developed in response to the needs of disadvantaged young people with physical impairments. Implicit in that discussion was the suggestion that there were significant differences among the Contact users in terms of abilities, dependence and attitudes. In this chapter I shall outline the extent and variation of their disadvantage, describe how they were introduced into the day centres and identify the principal divisions within the user body. The evidence demonstrates that for most of the Contact members, over two-thirds of whom were congenitally impaired, subjective disadvantage resulting from physiological causes such as limited mobility had been compounded by other factors including the nature of their education, lack of employment and relative social isolation. The data show that although all the user respondents were aware that day centre attendance was voluntary, many felt that they were offered little else when their education ceased. Although there was some homogeneity among this user group in terms of previous experience and general disadvantage, there were also discernible subdivisions within the group determined largely by degree of impairment and perceived dependence. These include two factions or cliques with contrasting attitudes toward disability, dependence and the day centres. These differences are explained with reference to the degree of impairment and differential socialization.

The chapter is divided into four inter-related parts. Since the majority of Contact members were congenitally impaired, the first part provides an overview of the likely consequences of a childhood with an impairment. The second looks at the users' social characteristics and relative disadvantages and provides an insight into their biographies. The third documents their introduction into the system and the fourth examines user interactions within the context of the Contact group.

### Impairment and Childhood

As we have seen in previous chapters, in contemporary Britain, as in most modern industrial societies, there is still a considerable cultural bias against people with impairments. This is manifest in institutionalized exclusion

from mainstream economic and social activity and stereotypical perceptions of the disabled as at best 'superhuman' and at worst, but still most commonly, 'less than whole'. These essentially negative perceptions are transmitted through language. For example, people with impairments are often referred to as 'invalids' or invalids (Hurst, 1984). But more broadly such perspectives are embedded in the very fabric of social encounters. The negative stereotype which the disabled endure is reinforced by the generalized ideal of physical perfection and competence that is presented in mass culture through the media and conventional recreational literature (Abberly, 1987). As a result, living with disability is generally associated with a life of poverty, social isolation and stigmatization or 'second-class citizenship' (Sieglar and Osmond, 1974). Consequently,

to become disabled is to be given a new identity, to receive a passport indicating membership of a separate tribe. To be born handicapped is to have this identity assigned from the moment of discovery and diagnosis. Both involve a social learning process in which the nuances and meanings of the identity are assimilated (Thomas, 1982, p. 38).

This social learning process was discussed in detail by Goffman in *Stigma* (1968). His analysis of the 'moral career', or changes in self-perception, of individuals with a socially stigmatized status, suggests that the acquisition of the devalued identity which usually accompanies impairment involves, initially at least, a two-stage learning process. The first relates to learning the beliefs and values of normal society and the general idea of what it would be like to be viewed abnormally. The second begins when the individual learns that s/he is viewed in this way and discovers the consequences of this perception. The timing and interplay of these two stages are crucial, Goffman claims, for future development of the individual's ability to adapt to her/his circumstances.

He suggests that this learning process, applied to persons with impairments, can be conceptualized in four ways. The first concerns the congenitally impaired and involves individuals being socialized into accepting their disadvantaged circumstances even while they are learning and incorporating the standards against which they fall short. The second also relates to those impaired from birth but involves individuals being shielded from the full extent of societal perceptions of the disabled by institutions such as the family until they enter the wider community either at school, or later during adolescence when looking for work. The third variant refers to individuals impaired later in life and concerns the re-evaluation of

self after the ascription of the disabled identity. Goffman's fourth model is less applicable to people with disabilities and concerns individuals socialized into an alien culture, who are confronted with the problem of self-reappraisal after learning that their adopted norms and values are not viewed as appropriate by those around them. Implicit in this analysis is the suggestion that the first pattern identified is the least psychologically problematic, if only because unlike the others it is a gradual process rather than a new experience.

While Goffman's analysis may be criticized because it is incumbent upon profoundly negative perceptions of impairment which ignore the material basis of society's oppression of people with disabilities (Finkelstein, 1980) and therefore precludes the experience of disability or adjustment as normal, it does provide a theoretical framework for understanding the different processes by which many people with impairments come to terms with a disadvantaged status. It is particularly useful in relation to childhood impairment and socialization.

Briefly, individuals learn the social norms and cultural expectations, or shared standards of behaviour, of society through the process of socialization. Primary socialization relates to the experience of childhood. It is generally regarded as the most important, and usually takes place within the family. Other important agencies of socialization include peer groups, the education system, occupational groupings and the work experience. Through interaction with 'significant others', which may include parents, siblings, peers or teachers, the child learns the meanings of 'significant symbols', or language and communication, and the role(s) s/he will be expected to perform, both as a child and adult. Socialization is not confined to childhood but continues throughout life.

Perceptions of self are therefore derived through social interaction. An individual comes to know who s/he is and how s/he is perceived through her/his interactions with others. We assemble a concept of self based on how we imagine others see us. Our sense of identity is therefore constructed on the basis of others' definitions. Consequently, how a child with a congenital impairment adapts to societal perceptions of disability will, initially at least, be greatly influenced by interactions within the family.

The birth of a child is usually regarded as a joyous occasion but the arrival of an infant with a disability is generally considered a difficult time for families. Parents are said to experience a mixture of emotions including shock, guilt, shame and helplessness, accompanied by feelings of

frustration and rejection for the child (Selfe and Stow, 1981). Some are said to over-compensate, which can in turn lead to other problems. For example, Meredith Davies (1982) points out that there may be a complete change in the lifestyle of the mother who, determined to love and care for her offspring, partly neglects other family members which can lead to marital difficulties. A contrasting view is that of Roith (1974) who has argued that the birth of a disabled child does not necessarily promote adverse reactions in parents. Although this debate remains largely unresolved, a major cause of family stress is likely to be the financial and practical problems of caring for the impaired child or children.

Disability in a child has a fundamental impact on the family budget. On the one hand, family incomes tend to be lower because the mothers of disabled children have fewer opportunities than mothers of non-impaired children to take paid work outside the home. On the other hand, extra expenses are needed for a wide variety of items including, most commonly, heating, transport and clothing (Baldwin, 1985). These problems are exacerbated further when families are situated at the foot of the class structure.

There is considerable evidence showing that the mortality and morbidity of the manual working classes is poorer than that of other sections of society (Black Report, 1981; Townsend *et al.*, 1987) but little showing the relationship between social class and impairment in children. One source, however, commenting on the fact that in a sample of 279 families with an impaired adolescent selected from the Family Fund's register, 1 only 32 per cent were headed by a non-manual worker (as against 40 per cent for the general population) stated,

The social class distribution may reflect a bias towards the manual classes applying to the family fund. It may also reflect a bias to manual social classes in the prevalence of severe disabilities in children. In all about three out of four of the young people in this sample lived in a disadvantaged home background where this included unemployed, low waged, elderly chronically sick or lone parents (Hirst, 1987, p. 64).

Whatever the cause, there is evidence that impairment in children does have an adverse effect on family life, often resulting in family breakdown. For example, a study of families with a child with spina bifida found a marked increase in family problems. Only one in four were free from difficulties and relationships within the marriage tended to deteriorate over

time. The divorce rate was twice that of the control group (Tew and Lawrence, 1974, reported in Meredith Davies, 1982). There is also ample evidence showing that these families face additional financial and social problems, particularly where the lone parent is a woman (Finer Report, 1974).

Because few families are equipped to cope with the emotional, financial and practical problems accompanying the birth of a child with an impairment, parents normally come into contact with a wide range of professional experts including doctors, health visitors, psychologists, educationalists and social workers. Consequently, professionals have a significant impact on both the family and the child's future. There are a number of views regarding the effects of professional intervention. Voysey (1975), for example, shows that parental attitudes and definitions are greatly influenced by their interactions with professionals or 'significant others'.

Another writer, however, suggested that parental perceptions of their child's disability were shaped by a number of other factors, including previous experience, social class, race and ethnicity (Darling, 1979). Booth (1978) maintained that parents adapted to the problems associated with their child's impairment in distinctly individualistic ways which struck a balance between professional definitions and their own life experiences. He concludes that parental appraisals of their child's disability are generally more influential than clinical perceptions and definitions. Whichever view is taken, the level of professional involvement in families where childhood impairment is present is likely to be far higher than that in families where it is not. This situation not only sensitizes the family and the impaired child to the functions and power of professionals, but it also helps to separate them from the rest of the community.

In addition, families where impairment is present are sometimes subject to what has been termed a 'courtesy stigma' (Bierenbaum, 1970). This refers to the situation where the negative attitudes surrounding disability are extended to the rest of the family. When this occurs the prejudice and ignorance which surrounds disability is projected onto other family members, particularly when they are out with the impaired child. This tends to confine social activities within the home and restrict social contacts to a limited number of close and considerate friends (Thomas, 1982), causing adverse reactions in parents which may directly or indirectly effect the developing child. A common cause for concern among professionals is parental over-protectiveness, where parents refuse to allow children with

impairments to take risks and grow up normally (Meredith Davies, 1982). On the other hand, it has been suggested that attachment and dependence cannot be measured, even in families where impairment is not present, and that it is far more difficult with disabled children to say which aspects of parental behaviour are unnecessary (Anderson and Clarke, 1982). Moreover, since many disabled children are separated from the family at a very early age, in hospitals or in residential schools for example, their primary socialization is very likely to be markedly different from that of their non-impaired contemporaries.

Besides being generally associated with parental deprivation and separation, childhood hospitalization also entails the learning of new roles and new relationships. Hospital admission necessitates that the child is thrust into what Parsons (1951) referred to as the 'sick role' and 'patient role' which are the precursors to the dependent or 'impaired role'. They are synonymous with freedom from normative role obligations, dependence and deference to professional authority. Davis' (1963) analysis of the hospital experience of children with polio outlines this process. He identifies the moral implications of what he terms the quintessence of protestant ideology, 'not whining for home' and the 'slow patient and regular pursuit of long-term goals' in order to get well.

For all children school is a particularly significant phase in development. For the child with disabilities it can be the start of a life-long process of stigmatization, or the beginning of normalization. For Goffman it is especially significant since interactions in formal education can ram home generalized perceptions of her / his devalued status for the stigmatized individual.

Public [normal state] school entrance is often reported as the occasion of stigma learning, the experience sometimes coming very precipitously on the first day of school with taunts, teasing, ostracism and fights. Interestingly the more the child is handicapped the more likely he is to be sent to a special school for persons of his kind, and the more abruptly he will have to face the view which the public at large takes of him (Goffman, 1968, pp.47-78).

The term special school refers to institutions for children termed 'handicapped, exceptional or in special need' (Barton and Tomlinson, 1984). While teasing and bullying are often discussed with reference to the placement of children with impairments in normal schools, it has been

reported that similar behaviour also occurs in segregated establishments (Anderson and Clarke, 1982).

Whether or not children with special needs should be placed in separate schools is a contentious issue, and one with respect to which parents are particularly vulnerable to the advice of professionals, notably educational psychologists (Tomlinson, 1981, 1982). It is frequently argued that due to the lack of practical skills, difficulties caused by physical abnormalities, the disruption caused by hospitalization, and poor facilities in normal schools, children with impairments are better suited in establishments where teachers are specially trained, and class sizes are smaller. Alternatively such institutions can be criticized on the grounds that they reinforce difference by segregating the impaired from the non-impaired. Moreover, because many of these schools are residential they compound this problem by removing the child from the family and the local community, and severing any community ties and any peer group contacts which may have been made (Oliver, 1983a).

There is evidence, however, to suggest that, largely due to a felt need to be with like-situated individuals, some children prefer this type of establishment (Hurst, 1984). It has also been suggested that in some cases children placed in these schools are able to achieve higher levels of independence than would be possible if they remained in the protective environment of the family. Additionally, it has been noted that some parents have difficulty maintaining that independence when the child returns home (Brimblecomb *et al.*, 1985). Conversely, others view these schools less positively.

One study of the experience of impaired pupils in residential schools claimed that they went through several distinct phases. These included 'disorientation' due to the severance of domestic ties and 'depression' as a result of their new-found status given their placement with peers with similar conditions who had not been cured. This was followed by a period of 'pre-adolescent revolt', before moving into a state of 'acceptance' (Minde, 1972). In addition, since many of these establishments bear some, if not all, of the main features of a 'total institution', there is always the danger of 'institutionalization', where the resident begins to prefer life inside, rather than outside the institution (Goffman, 1961). There are also data showing that many special schools do not provide either an adequate education or the skills necessary for adulthood.

All modern education systems, including special schools, purport to fulfil at least two explicit functions: (a) socializing individuals into the norms and values of society, and (b) providing them with the necessary training to find work in accordance with societal needs. In a modern technologically advanced society educational achievement is essential for all young people. For those whose employment opportunities are limited as a result of physical impairment, it is crucial (Hurst, 1984). Yet one commentator has argued that many special schools do not provide even the barest rudimentary knowledge which constitutes a normal primary school curriculum (Tomlinson, 1982), condemning these students to a lifetime characterized by 'dependence and powerlessness' (Barton and Tomlinson, 1984).

There is plenty of empirical evidence to support these claims. For example, an analysis of spina bifida children reported that over a third were considered retarded in reading skills and a large proportion were deficient in maths abilities, although they had no acknowledged mental defect (NFER, 1973). The government-sponsored report on special educational needs stated that

The evidence presented to us reflects a widespread belief that many special schools underestimate their pupils' abilities. This view was expressed in relation to all levels of ability and disability (Warnock, 1978).

The serious implications of this situation and the ensuing disadvantage caused for individuals with impairments have been reiterated by many writers in the past decade. In a recent review of research about disabled young adults' preparation for and movement into work, which covered research dealing with both normal and special education, Parker stated:

adequate school leavers' programmes for those with special needs still seem to be the exception rather than the rule. The opinions of both young people and their parents indicate a considerable gap in preparation for life beyond school. Young people with disabilities, especially when they are physical, are less likely to be placed in work experience schemes than other pupils (Parker, 1984, p. 71).

Although there has been some expansion in further and higher education for students with special needs in recent years, the proportion of physically

disabled students remains small in comparison to the numbers of disabled people in the population as a whole (Hurst, 1984; Stowell, 1987). One of the main obstacles relates to environmental factors and problems of access and support. While many colleges can and do accommodate students with learning difficulties and mental handicaps, a recent national survey conducted for the Department of Employment by the National Bureau for Handicapped Students (renamed 'SKILL' or the National Bureau for Students with Disabilities in 1988), found that three in five colleges 'might' have to deny a place to students with physical handicaps because of access difficulties or the absence of the 'necessary support' (Stowell, 1987). There is a dearth of analyses of the experience of further education from the perspective of people with physical impairments (Hurst, 1984).

Although it is often said that further education enhances social and work skills and improves the likelihood of employment, this is not the case with regard to teenagers with impairments (Kuh *et al.*, 1988). There is a substantial and growing body of evidence showing that unemployment is disproportionately high among this section of the population (Brimblecomb *et al.*, 1985; Cantrell *et al.*, 1985; Hirst, 1984, 1987; Kuh *et al.*, 1988). People are categorized through work, or paid employment, in terms of class, status and influence. Apart from income, work provides a sense of identity and self-esteem, opportunities for social contacts outside the family home, skill development and creativity, as well as a sense of obligation, time and control (Fagin and Little, 1984). It is particularly important for young adults, as work is generally regarded as the major factor which determines the successful transition from childhood to adulthood. For example, a recent Department of Education and Science study of the views of young people found that employment was seen as defining adulthood and unemployment was the most significant area of concern.

Employment was the most important symbol signalling entrance into the adult world and was therefore a goal all were striving towards. Unemployment robbed the individual from successfully crossing the boundary between adolescence and adulthood and forced him/her back into a role of dependence on the adult world (DES, 1983, quoted in Kuh *et al.*, 1988, pp.4-5).

In addition to the general hostility of some employers towards employing people with impairments, it has been suggested that some bosses feel that disabled people are only capable of performing limited tasks. In times of recession when there is a surfeit of labour these problems are made worse (Hurst, 1984). For individuals excluded from the world of work due to

physical impairment, the economic, social and psychological implications are clear. Sheltered workshops are sometimes proposed as an acceptable alternative, but since by definition these establishments are segregative, they restrict social interaction with the able-bodied and consequently do little to eliminate a disabled identity.

The teenage years are generally associated with the concept 'adolescence'. While there is no general agreement regarding the duration of the adolescent period, it denotes a psychological process which begins with the individual's awareness of her/his pubescent physical changes and extends to a 'reasonable resolution' of her / his social identity. For most this is said to occur between the ages of 11 and 21 (Anderson and Clarke, 1982). Although there is little systematic data to support this view, some writers see this period as a process of identity formation which involves an emotional separation and detachment from parents (Erikson, 1968). To live independently from parents is commonly perceived as the second most important goal for young people (Hirst, 1987), following the acquisition of paid employment. It is a period in which individuals are said to acquire and/or be ascribed new roles. But the acquisition of new roles is frequently problematic and sometimes associated with psychological maladjustment and conflict, notably with parents. While it is a period regarded as difficult for most children, several studies have shown that adolescence is especially difficult for people with physical impairments.

For many young people with impairments adolescence signifies a growing sense of difference between themselves and their able-bodied peers. In the post-school years many teenagers become critically aware of the future and the limits which their disabilities and society impose upon their performance of a full complement of adult roles (Thomas, 1982). This can cause severe psychological problems which one source referred to as the 'slough of despond' (Brimblecomb *et al.*, 1985). One of the most influential studies concerned with these issues compared the post-school experiences of teenagers with congenital impairments to those of the non-impaired, and found that adolescence with disability was synonymous with four main characteristics. These were: (a) a high incidence of dissatisfaction concerning their social lives, particularly during the post-school years, (b) the feeling that they had little control over their lives and knew little about their 'handicaps' or the services available, (c) a poverty of choice available to those unable to find open employment, and (d) an ill-preparedness for the realities of life as adults (Anderson and Clarke, 1982). Their general lack of preparation for the adult world reflected the fact that they had been socialized into a life of social and economic dependence

which would be unacceptable for other sections of the population. It is not surprising that those individuals disabled in adolescence are reluctant to accept this devalued and dependent position.

The evidence clearly suggests that the experience of childhood for those with impairments is very likely to be different to that of the able-bodied, that any subjective disadvantage resulting from impairment is frequently exacerbated by other economic and social factors, and that as a result they face a future of extreme economic and social disadvantage, dependent on both their families and/or the state. The following section shows that many, if not all, of the considerations discussed above were applicable to most Contact users.

### The Main Social Characteristics of the Contact Users prior to their Introduction into the Day Centres

In this section I shall examine the data gleaned from both user interviews and, where appropriate, official day centre records regarding the users' life experiences before they began using the day centre service. It is divided into five separate parts covering (a) age distribution and social class, (b) impairments, (c) education, (d) work experience, and (e) accommodation. The evidence shows that besides physical impairments, the majority of this user group were seriously disadvantaged in terms of education and work experience and were dependent on their families for domestic arrangements. Consequently they were unable to attain the necessary economic and social independence normally associated with adulthood.

#### *(a) Age Distribution and Social Class*

Of the thirty-six Contact users fourteen were female. One of the group, Wendy, was from an Afro-Caribbean background. One male named Mark was also black, but left shortly after the study started because he was found a place in a residential institution outside Contact's catchment area. The average age of the Contact members was 22.5 years. Eight of the group were 25 or over, the oldest being 30, Eight were under 20. The youngest was 17. In respect of the Registrar General's occupational classification (OCPS, 1980) only four of the sample were originally from homes where the head of the household was a non-manual worker. At the time of interview, apart from Wendy and Clive who had been living in local authority homes since the ages of five and seven respectively, fifteen respondents lived in households that were characterized by unemployment, elderly, chronically sick or lone parents. Of the three not interviewed, Amy

and Alison were from one-parent families and Michael lived in a foster home. This pattern is particularly significant considering the mounting evidence of the financial burden endured by families caring for children with impairments.

*(b) Impairments*

Including Amy, Alison and Michael, twenty-five of the thirty-six Contact members were congenitally impaired. Fourteen were born with cerebral palsy and seven with spina bifida and hydrocephalus. Spina bifida describes a number of congenital malformations of the spine which sometimes causes paralysis. It is often accompanied by hydrocephalus which refers to excessive fluid around the brain. Cerebral palsy and spina bifida are the two most common causes of impairment in children in modern Britain (Anderson and Clarke, 1982).

Of the remainder congenitally impaired, one girl, called Molly, was born with curvature of the spine and another, Sheila, had dystrophic dwarfism. She was barely 122 centimetres tall. Karen, a rubella victim, had no overt physical impairment but her activities were inhibited by respiratory and heart problems. Two males had contracted hereditary degenerative diseases. Gavin had muscular dystrophy and had been unable to walk since he was 10, and Billy's Friedrich's ataxia became overt in his 16th year. Two other males became impaired due to severe cerebral haemorrhages. Matthew's was caused by meningitis which he contracted at 8. It left him a partial hemiplegic. Bruce's paraplegia was the result of a brain haemorrhage caused by a benign brain tumour when he was 5. Including Amy, four of the Contact members were prone to epileptic-type seizures. These included Bruce, Andy, a 27-year-old with cerebral palsy and Angela, who had spina bifida. Nancy was born with hydrocephalus. Roger, the eldest in the group, contracted a neurological disorder of unknown origin with similar symptoms to muscular sclerosis at the age of 25. He was easily tired, extremely weak and walked with a permanent stoop. Five males, John, Charles, Spike, Philip and Robert, were impaired as a result of road traffic accidents.

Other than Robert, who would be termed functionally blind although retaining approximately 4 or per cent of what he could see before his accident when his eyesight was considered normal, a number of the group had noticeable eye problems. Several wore thicker than normal spectacles and held books or objects of interest unusually close to their faces when looking at them. Three users, Billy, John and Norman, said they were

supposed to wear glasses for reading but chose not to, and five others had pronounced squints. Margaret, Gavin Nancy, Millie and Curt would be regarded as grossly overweight, a common problem among teenagers with mobility problems (Anderson and Clarke, 1982).

Although Nancy had no problems with walking, she, along with the other four, who were all reliant on wheelchairs, had been on permanent diets for as long as they could remember.

Although the criterion for group membership was officially physical impairment, one user, Richard, had no such recorded condition. He was said to have experienced 'behavioural difficulties' as an infant. He had joined the group in 1982 on a probationary basis, largely because he had attended the same school as most of the other group members. Apart from a spell in Spain, where his mother went to work in a bar, he has been with the group ever since.

It was clear from the formal interviews that while a minority knew a great deal about their conditions, *Joyce*, *Jamie* and *Marilyn* being notable examples, the majority knew relatively little. Eleven did not know the name or the cause of their impairments. In addition, all the group had spent lengthy periods in hospitals, many before they went to school. Several could recall first meeting other Contact members while in hospital, This applied not only to the congenitally impaired. *Matthew*, for example, was at one stage in the same ward as *Charles* and *Spike*.

In terms of mobility, sixteen of the group were solely dependent on wheelchairs. Three could not walk without crutches and *Sheila*, who had a double prosthesis for her legs, used a walking frame when indoors. These four all used wheelchairs when outside the centres or the family home. At least five of the remainder were receiving mobility allowance, which at the time of this study was a state benefit paid to individuals who were deemed by a doctor to be unable to walk more than 200 yards due to physical impairment (see Disability Alliance, 1986/7), because of their unsteady gait. Only *Richard* and *Robert* walked normally, although *Robert* seldom moved about without a guide. Five had restricted use of both upper limbs and a further ten had limited use of one arm or hand. *Joyce*, *Billy*, *Karen*, *Marilyn* and *Spike* all had mild speech impairments. Although these defects did not apparently impede verbal communication they were a source of embarrassment since they all 'slurred' their words, which they felt made them sound 'thick' or 'stupid'. Ten Contact members were incontinent and a further three needed help with toileting.

Table 11 Age and Principal Impairments of the Contact Users

Name	Age	Age at onset of impairment	Cause of impairment	Extent of Impairment		
				Lower Limbs	Upper Limbs	Others
Margaret	23	birth	SB/HC	both	-	-
Tony	18	birth	CP	both	both	-
Joyce	25	birth	CP	both	both	-
Billy	17	15.5	FA	both	-	-
Andy	27	birth	CP	one	one	epilepsy
John	20	17	RTA	both	both	-
Sheila	20	birth	DD	both	-	-
Jamie	24	birth	CP	one	one	-
Sally	19	birth	SB/HC	both	-	-
Karen	18	birth	Rubella	-	-	respiration/ heart
Molly	25	birth	SC	-	-	-
Matthew	24	8	Meningitis	one	one	-
Paul	18	birth	CP	one	one	-
Gavin	19	birth	MD	both	both	-
Norman	22	birth	CP	both	-	-
Barry	18	birth	CP	one	one	-
James	22	birth	SB/HC	both	-	-
Henry	20	birth	CP	one	one	-
Marilyn	25	birth	CP	one	one	-
Bruce	20	5	BT	both	one	epilepsy
Nancy	20	birth	HC	-	-	-
Angela	21	birth	SB/HC	both	-	epilepsy
Millie	21	birth	SB/HC	both	-	-
Richard	20	unknown	behavioural	-	-	-
Wendy	18	birth	CP	one	-	-
Curt	21	birth	SB/HC	both	one	-
Roger	30	25	NDUO	-	-	-
Elizabeth	23	birth	CP	one	-	-
Charles	27	17	RTA	both	both	speech
Spike	21	18	RTA	one	-	co-ordination
Philip	28	24	RTA	one	one	-
Robert	26	20	RTA	-	-	eyesight
Clive	21	birth	SB/HC	both	-	-

Key

SB =	Spina Bifida	MD =	Muscular Dystrophy
CP =	Cerebral Palsy	BT =	Brain Tumor
RTA =	Road Traffic Accident	HC =	Hydrocephalus
DD =	Dystrophic Dwarfism	FA =	Freidrich's Ataxia
NDUO=	Neurological disorder of Unknown disorder	- =	no impairment

Source: user interviews and official day centre records

### *(c) Education*

Twenty-six of the respondents had attended special schools of one kind or another at some stage during their pre-16 school years. Nine had received some of their education in residential schools, seven of these between the ages of 5 and 11. Sheila had spent all but one of her school years in this type of institution. Moreover, five of the group had attended the same boarding school and twenty-two had been to the same day school, which I shall call the Christy Brown School.

Christy Brown is described in official documents as 'an LEA school catering for the special needs of physically handicapped pupils between the ages of 2 and 16' (Huchinson, 1987). It is non-residential with a capacity for 120 children. The staff includes teachers, special unit teachers for communication aids and special needs, nursery nurses, nurses, care attendants and physiotherapists. The school provides facilities for education and 'personal and social development'. All pupils have transport provided by the school and the school day starts at 9.30 a.m. and finishes at 3.30 p.m.

Of those who attended residential schools only Clive maintained he was happy to have left home because his parents were in the process of separating at the time. All the others in this group said they had not wanted to go, but with hindsight believed it had been beneficial in terms of improving self-determination and personal independence. Seven of the sample had attended both special and normal schools. One of them, John, had been assigned to a school for children with learning difficulties when he was eleven, six years before the accident which caused his paraplegia. Only seven members of Contact had attended ordinary state comprehensives for their entire school lives. Of these, two had manifested impairments before their sixteenth birthday.

Sixteen of those who had been to special schools said they were dissatisfied with their education. Fourteen had difficulty with the three Rs, and ten reported problems when handling money. All blamed their schooling for this state of affairs. Some felt their teachers had concentrated far too much on their physical problems and not enough on their formal education. Of the seven who had attended both special and normal schools, Karen, Nancy, Richard and Wendy, all ambulatory and marginally physically impaired when compared with others in Contact, had profoundly unpleasant memories of time spent in ordinary schools. They each said they were targets for bullying by non-impaired children and were much

happier after they returned to the special school. All had been introduced to a normal school environment before the age of 8 and none stayed longer than a year. Andy and James both went into an ordinary comprehensive when they were 14. Andy was non-committal about the experience, but James was relatively positive about it, although he admitted he missed his former classmates.

The highest achievers were those who had gone to ordinary state or segregated boarding schools. Robert had seven GCE O level passes and Charles, Philip and Roger each had four. Billy and Matthew got one CSE apiece. Spike maintained he had had little interest in school and said that after the age of eleven he had done his best 'to avoid the place'.\* Andy got one GCE and one CSE and James passed CSE maths. Of those who had been in residential institutions at some point, Sheila had attained three CSEs, Marilyn two and Joyce one.

None of the Contact group had any experience of higher education but nineteen had been on some form of post-16 provision. Excluding Roger, Charles, Philip and Robert who had been to college in conjunction with their employment before their disablement, sixteen users had been on vocational education and independence-type courses for the physically impaired. Andy and Jamie had attended residential colleges for one and two years respectively, and Tony was actually on one of these courses at the time of the study. He only used Contact during the vacations. Robert had been on a three-month independence training programme for the visually impaired at a college in Torquay in 1984, three years after his first accident and one year after his second when he was knocked down by a car.

The majority had been on the same independence-type course, albeit not all at the same time. It was a one or two year scheme depending on perceived need. Six had taken the two-year option and seven the one. Although this course was situated in an able-bodied college it was clear from the numerous informal discussions with experience-students that there had been little interaction between them and the non-impaired, either in the classroom or the common room. The reasons for this were unclear.

*Table 12 Education and the Contact Users*

Name	Type of school		Qualifications received	Further Education		Qualifications received
	Normal	Special		Normal	Special	
Margaret	-	12yrs	-	-	2 yrs	-
Tony	-	12yrs R	-	-	1.5yrs R	C&G
Joyce	-	12yrs R	1 CSE	2 yrs	2 yrs	6 GCE
Billy	12 yrs	-	1 CSE	-	-	-
Andy	2 yrs	10 yrs	1 CSE	2 YRS*	1 yr R	1 GCE
John	6 yrs	6 yrs	-	-	-	-
Sheila	-	12 yrs R	3 CSE	-	2 yrs	-
Jamie	-	12 yrs R	-	-	2 yrs R	-
Sally	-	12 yrs	-	-	-	-
Karen	1 yr	11 yrs	-	-	-	-
Molly	-	12 yrs	-	-	2 yrs	2 CSE
Matthew	12 yrs	-	1 CSE	-	-	-
Paul	-	12 yrs	-	-	1 yr	-
Gavin	-	12 yrs	-	-	-	-
Norman	-	12 yrs	-	-	-	-
Barry	-	12 yrs R	-	-	1 yr	-
James	2 yrs	10 yrs	1 CSE	1.5 yrs	1 yr	C&G
Henry	-	12 yrs	-	-	-	-
Marilyn	-	12 yrs R	2 CSE	-	-	-
Bruce	-	12 yrs	-	-	-	-
Nancy	1 yr	11 yrs	-	-	-	-
Angela	-	12 yrs	-	-	1 yr	-
Millie	-	12 yrs	-	-	1 yr	-
Richard	1 yr	11 yrs	-	-	2 yrs	-
Wendy	1 yr	11 yrs	-	-	1 yr	-
Curt	-	12 yrs	-	-	-	-
Roger	12 yrs	-	4 GCE	-	-	-
Elizabeth	-	12 yrs	-	-	2 yrs	-
Charles	12 yrs	-	4 GCE	1 yr*	-	speech co-ordination
Spike	12 yrs	-	-	-	-	-
Philip	12 yrs	-	4 GCE	2 yrs*	-	-
Robert	12 yrs	-	7 GCE	4 yrs*	3 mts R	BTEC
Clive	-	12 yrs R	-	-	1 yr	-

**Key**

Yr/s = years  
Mths = months  
\* = part time  
C&G = City & Guilds  
BTEC = British Technical Education Council Award

CSE = Certificate of Secondary Education  
GCE = General Certificate of Education  
R = residential

Source: user interviews

Three respondents had been on courses for the non-impaired. Joyce had studied full-time for two years for GCE O levels and received six passes. Andy successfully completed a two-year part-time GCE maths course and James had been on an eighteen-month computer training scheme. All three viewed these experiences positively because they had enjoyed the social aspects of college life.

But they were clearly disappointed that their efforts had not led anywhere, particularly with regard to finding employment.

#### *(d) Work Experience*

Only seven of the thirty-six Contact users had any experience of paid employment other than government supported work or training programmes. Charles, Roger, Spike, Philip and Robert were not impaired when in work. None of them have worked since the onset of their impairments. Of the twenty-eight labelled 'disabled' at 16, only two had any experience of a proper job. Andy got himself some part time work in a local garage 'just' elpin' out'. \* But he had to give it up when his back was injured after being hit by a car on his way to work. He had been knocked down twice in his life, once when he was 10 and again in 1984 at the age of 24. When Marilyn left school her careers officer got her a job in a local branch of a well-known British-owned department store. She was sacked after three days on the grounds that she constituted a fire risk. Her father then secured her a post in a local supermarket filling shelves. She was dismissed after six months after a management change, because her work was considered too slow.

Four of the group had been on government work schemes which at this juncture were referred to as the 'Youth Opportunities Programme'. John, who was not impaired at the time, moved straight from school on to one of these schemes. His attendance was cut short after ten months by his accident. Matthew went on a similar programme to learn the upholstery trade. Molly and Nancy worked in the kitchens of old people's homes to gain an insight into the catering industry. Although these three all said that they enjoyed the work and encountered no difficulties doing it, when the government support finished so did the jobs. They had not worked since. It is important to note that Andy, Marilyn, Molly and Nancy were moderately impaired compared to others in Contact. They were all ambulatory and although Andy, Matthew and Marilyn each had restricted use of one arm, they each felt this did not pose a major problem. Five of the group had been directed toward the Adult Training Centre (ATC) run by the Spastics

*Table 13 Work Experience and the Contact Users*

Name	ATC Duration	YOP Duration	Open Employment	
			Description	Duration
Margaret	1 month	-	-	-
Tony	-	-	-	-
Joyce	-	-	-	-
Billy	-	-	-	-
Andy	10 weeks	-	labourer	6 months (PT)
John	-	10 months	-	-
Sheila	-	-	-	-
Jamie	10 weeks	-	-	-
Sally	-	-	-	-
Karen	-	-	-	-
Molly	-	12 months	-	-
Matthew	-	12 months	-	-
Paul	-	-	-	-
Gavin	-	-	-	-
Norman	1 weeks	-	-	-
Barry	-	-	-	-
James	-	-	-	-
Henry	2 weeks	-	-	-
Marilyn	-	-	shop work	6 months
Bruce	-	-	-	-
Nancy	-	12 months	-	-
Angela	-	-	-	-
Millie	-	-	-	-
Richard	-	-	-	-
Wendy	-	-	-	-
Curt	-	-	-	-
Roger	-	-	various	9 years
Elizabeth	-	-	-	-
Charles	-	-	engineer	1.5 years
Spike	-	-	soldier	1 year
Philip	-	-	various	6 years
Robert	-	-	surveyor	4 years
Clive	-	-	-	-

**Key**

- ATC = Adult Training Centre
- YOP = Youth Opportunity Programme
- PT = Part time working

Society before their involvement with Contact. None of them viewed the experience positively in terms of skill acquisition or personal development. They all maintained that the high percentage of people with mental handicaps in this establishment had been the single most important reason for leaving. The stark absence of work experience among the majority of Contact members is particularly alarming considering the importance our society places on gainful employment and the long-term economic, social and psychological implications for the individual due to the lack of it.

*(e) Accommodation*

Only three of the Contact users had set up homes of their own. Two others were living in long-stay residential institutions and the remainder were living with one or both of their parents or guardians. Two of the adventitously impaired members of this group had moved out of the family home before the onset of their impairment, but had to move back in after they became disabled.

Philip had been married for two years before his accident and was living with his wife and daughter. Jamie and Andy were the only two congenitally impaired Contact users who had managed to become independent from their respective parents, albeit both were from one-parent families. The former shared a council flat with his disabled girlfriend Alice and their baby daughter, prior to which he had lived with his father. Alice was a partial hemiplegic which was caused by a stroke when she was 25. Before her pregnancy in 1986 she had been a regular day centre user. Andy was the only Contact member who lived alone. He had a small bedsit about half a mile away from his mother's home which he visited almost daily.

Although Wendy lived in a children's home with able-bodied peers, she was deeply unhappy there. She felt the other children were always making fun of her

*Table 14 Accommodation and the Contact Users*

Name	User's home	Others living in home	Current occupation of male head of household
Margaret	PH	M/F	builder
Tony	PH	M	-
Joyce	PH	M/F	overhead cable jointer
Billy	PH	M/F/2S	unemployed
Andy	OH	-	unemployed
John	PH	M/F	factory worker
Sheila	PH	M/2S	-
Jamie	OH	G/D	unemployed
Sally	PH	M/F/2S	telephone engineer
Karen	PH	M/F/1S	lay preacher
Molly	PH	M/1S	-
Matthew	PH	M/F	motor mechanic
Paul	PH	M/F/1S	auditor/cashier
Gavin	PH	M	-
Norman	PH	M	-
Barry	PH	M/F/A	retired
James	PH	M/F	salesman
Henry	PH	M/F	lorry driver
Marilyn	PH	M/F	builder
Bruce	PH	F	gasfitter
Nancy	PH	F	cook
Angela	PH	M/F	motor mechanic
Millie	PH	M	-
Richard	PH	M/1S	-
Wendy	RH	unknown	-
Curt	PH	M/1S	unemployed
Roger	PH	M/SF	engineer
Elizabeth	PH	M/F/1S	council worker
Charles	PH	M/F	retired
Spike	PH	M/SF	unemployed
Philip	OH	W/D	unemployed
Robert	PH	M/F/2S	toolmaker
Clive	RH	unknown	-

Key

PH	=	parental home	SF	=	stepfather
OH	=	own home	S	=	siblings
RH	=	residential home	G	=	girlfriend
M	=	mother	D	=	daughter
F	=	father	A	=	aunt
			W	=	wife

and desperately wanted to move somewhere else. Clive was situated in a residential institution for the physically impaired run by the local authority and had been since he left college. While he was used to life in segregated institutions and had few happy memories of life with his parents, he disliked his present circumstances since he had no privacy and little independence. Of the remainder, Bruce and Nancy lived with their respective fathers and seven others with their mothers. Although they had both left home before their impairment, Roger and Spike were living with their mothers and stepfathers. The former had initially left because he could not get on with his mother after his father had died and did not like her choice of boyfriend, the man who later became his stepfather. Both Spike's mother and stepfather were disabled. She had multiple sclerosis and he rheumatoid arthritis. Both were regular attenders at the Alf Morris centre. Seven of the sample lived in households where there were siblings present.

For the majority, therefore, some degree of dependence on parents was inevitable. With regard to the problem of parental over-protectiveness, fifteen users complained that they were 'mollycoddled' by one or both of the principal family members. Nancy, for example, said that as she grew older her father's attitude towards her seemed to be becoming more restrictive. Joyce felt she was 'smothered' by both her parents. Nine respondents expressed an awareness of regular conflict within the family home, either between themselves and one or, where appropriate, both parents which they felt was the result of their impairment. In most cases this was related to their need for independence and parental reluctance to give it.

I have focused on the main social characteristics of the Contact users and have shown the majority to have been disadvantaged both with regard to open employment and residential independence of parents, the two most important prerequisites for entry into the adult world. Most of the Contact users were from the manual working classes and were brought up in environments characterized by some form of parental or economic deprivation. Although there was some variation in the level and cause of impairment, the majority were congenitally impaired and mobility was a major problem for most. Consistent with the findings of other studies in this field, there was a lack of knowledge among respondent about their impairments. Although all definitions are problematic, I believe that the majority would be regarded as moderately to severely impaired by the general public.

Most of the group had spent much, if not all, of their childhood in segregated environments, in hospitals, special schools and in some cases

residential institutions. Many had attended the same hospitals and schools. They expressed a high degree of dissatisfaction about their education, particularly in terms of their academic achievements, which adds weight to some of the criticisms levelled at special schools. Those who had attended residential schools viewed the experience positively in terms of independence skills. Although over half of those impaired at 16 had been on some form of vocational independence training in further education and a minority had gone on to courses for the non-impaired, these experiences did little to help them find a job.

The experience of paid employment for those disabled at 16 was extremely limited. This was in stark contrast to that of the five adventitiously impaired who had never been out of work prior to the onset of their disability. It is significant that none had worked since. As a result all were economically dependent on the state. In addition, the data show that most of the group were dependent on their families for accommodation and that there was a high degree of dissatisfaction among many concerning their domestic arrangements.

In short, the majority of these young people entered the post-education phase with few opportunities to develop control over and responsibility for their own lives. They had literally been socialized into a life of economic and social disadvantage and child-like dependence. The remainder were thrust into this disadvantaged position after the onset of their impairment. It is clear that all were particularly dependent for the quality of their future lives on the services provided for them. The following section examines how they were channelled into the day centres and how they have adapted to this situation within the context of the Contact group.

#### How the Contact Users were Introduced to Day Services

Since day centre attendance is not compulsory and is frequently regarded as the least desirable option available to young people with physical impairments, it is important to establish how and why the individuals in the Contact group first became involved with the service. The data in this section show that the majority entered the system for explicitly social reasons, either to maintain long-standing peer group relations or to escape the debilitating social isolation encountered when their education finished. It is also apparent that some were directed toward the system to assist in their rehabilitation. The evidence in this section underpins the poverty of economic and social opportunities available to these young people after formal education, shows how little control they had over their lives during

this period and highlights how influential professionals are with regard to shaping their future.

Throughout the study, eligibility for a day centre place for the younger physically impaired, as for other potential day centre users, was dependent on a recognized physical impairment and a referral by an acknowledged professional such as a doctor, social worker or careers officer. If an individual contacted one of the centres with a view to becoming a user, they were directed to their nearest social services offices where someone would furnish them with the necessary document. All senior staff maintained that refusal was almost non-existent.

Unlike other day centre users, however, the introduction to the idea of day centre use for the younger impaired who had been through some form of special education, could be either a collective or an individual experience. The Christy Brown school and the local college of further education which ran courses for students with special needs periodically organized visits to the Contact group for students who the school or college staff felt would have difficulty finding alternatives. The visits were initiated by careers officers at the school and college and organized through consultation with Contact staff. At least nine of the users vividly recalled being made aware of Contact through this method.

The practice began shortly after Jayne had forged links with these two institutions in 1981-82, when she was getting the group started. Recent amendments to the Youth Training Programme, however, such as the introduction of the YTS2 scheme in April 1986 (Cooper, 1986), have meant that these visits have been less frequent in recent years and that the level of impairment of those recommended for referral has become noticeably more severe.

One of these visits took place on 14 May 1987 as my involvement with the centres was drawing to a close. One Wednesday morning at the Alf Morris centre, Jackie, who was at this time the senior activity organizer (SAO) for Contact, casually announced that in the afternoon the group was to be visited by a party from the local college of further education. No special arrangements were made, no extra tidying up was done and none of the users or staff seemed unduly concerned about the event. When I asked Jackie why no special preparations were made, she told me she did not wish to give any false impressions of the group which might detract from the relaxed social atmosphere which normally prevailed. At about 1.45 p.m. the party arrived. It consisted of Graham, the careers officer at the college,

a home economics tutor and four students, three boys and a girl. Two of the boys were wheelchair-bound and had muscular dystrophy. The other youth walked using arm crutches but had a severe speech impairment. He had been seriously injured in a motorcycle crash. The girl needed no assistance walking but had an unsteady gait due to cerebral palsy. She was also an epileptic.

Upon arrival the party were casually introduced to everyone by Jackie, although it was clear that for many no introduction was necessary, since no sooner had they arrived than the newcomers began to renew acquaintances with those Contact members who had recently attended the college, and/ or were introduced to others they did not know by those they did. Gradually they dispersed into a number of subgroups where the general conversation revolved around recent developments at the college and life in the day centres. As far as I could tell, none of the users were derogatory in their references to the Contact group or the Alf Morris centre. The college staff proceeded to chat with some of their ex-students and the centre personnel. Once the interaction was well under way, Jackie and Graham adjourned to the Contact office where the relevant information about the prospective users was discussed. After about fifteen minutes they returned and Contact staff served tea and biscuits to the visitors in the larger of the two rooms. This was the only concession to formality which occurred during the entire afternoon. At 3.00 p.m. Graham decided it was time to leave. Goodbyes were exchanged and the party left. The visit was viewed by everyone in the Contact group as a largely social event, but they were aware of its purpose since many had been through a similar experience themselves.

Individual introductions generally followed a similar pattern but the candidates would be brought to one of the centres by the professional making the referral. These visits could also include members of the individual's family or, if s/he lived in a residential home, one of the institution's staff. This occurred twice while I was with Contact. On 2 July 1986 Paul was brought to Alf Morris by Graham from the college mentioned above, and a similar sequence of events took place, apart from the tea and biscuits. According to senior Contact staff, however, it was more usual for those making the referral to contact the SAO, who would then either visit the potential user and her/his family at home and subsequently arrange a visit to the centres, or, if this was not deemed appropriate or necessary, they would be invited to have a look round. This happened on 3 November 1986 when Jayne brought Clive and the manager of the residential home

where he lived to Alf Morris. Both Paul and Clive knew other Contact users before their visits and both joined the group one week later.

At some stage during these proceedings a discussion between the SAO and the users concerning the facilities offered, proposed attendance and transport arrangements would take place. Although not always possible, these discussions were seen as crucial by senior Contact staff for three reasons. Firstly, the data on many of the referrals is considered grossly inadequate in relation to the degree of impairment, abilities, and the level of disadvantage experienced. Initially some referrals contain as few as thirty words, including only the individuals' name, address, date of birth, GP's name and address, and primary disability. And according to Andrew, the officer in charge (OIC) at Alf Morris, the latter 'may only be three letters - CVA (cerebral vascular accident or stroke)'.\* There is often little reference to the extent of the individual's impairment, secondary impairments, previous experiences, emotional state, or family background. Arguing that too much information could influence their attitudes and subsequent interactions with users some staff easily defended the paucity of data on referrals. They felt staff/user relations should be constructed on first-hand experience and not on data received from external sources.

A second reason for an initial discussion with prospective users is to ascertain how their needs could be accommodated within the service on offer. For example, some people might require a five-day service, others less. Thirdly, for some prospective Contact users, either because of their youth or degree of impairment, the initial decision to attend day centres is not always theirs. Consequently their expectations of the service, and sometimes those of their families, may not correspond to the facilities and services provided.

These considerations were underpinned when related to the users' accounts of their preliminary involvement with the day centre system. While some appear to have begun using the service without much objection, others entered the system with varying degrees of reluctance. At least three maintained they were given little opportunity to do anything else. Two of the group joined Contact before they left school, simply because there was no one at home to look after them during the long summer holidays. They appeared to be relatively happy with this situation and had given no serious thought to the alternatives. Both were confined to wheelchairs and had been educated in special schools throughout their lives. Four others started with the group a soon as they left formal education.

Although they were all aware that the day centre option was voluntary, they viewed it with an air of fatalistic optimism. Sally for example stated,

'We cem round from school an' I knew a few of 'em 'ere, Margaret an' Norman an' them. An' it looked alright, nobody seemed to be tellin' 'em what to do or owt. So I couldn't see any point in goin' to college so I cem traight 'ere.'\*

Although familiar with the day centre service through school or college, many of the group initially rejected the idea of attendance in the hope that they would find something else. Over two-thirds had previously held distinctly negative views of the day centre option, a view shared by many similarly disadvantaged young people Oowett. 1982; Kent *et al.*, 1984). However, after protracted periods of inactivity, which ranged from a matter of weeks to almost a year in one case, they each decided that it was better than nothing and contacted either Jayne or their social worker. In all, nine joined Contact via this method. A typical example was Sheila who had been made aware of the group by the careers officer at college, but had not bothered to have a look round because she anticipated finding a job. IJ,

'I wasn't very interested when she [the careers officer] was on about it at college. I thought I'd get something better. ...But it didn't work out like that. As soon as I left college I was quite stuck. So after about eight weeks I thought I'd better do something about this 'cos I was gettin' really fed up. So I rang Jayne and asked her if I could come and have a look round. And. ..., I started a week later.' \* -Sheila

Several of the users interviewed felt that, at the outset at least, they had little choice whether or not they should begin using the service. Four said that the decision to take up this option had been made by their parents in an effort to find something to do and get them out of the house. Nancy, for example, stated,

'Me dad just said "a kind o' social worker's been". He says to me "I've got you in like a day centre where it'll get you out an' about to meet friends". So I says, "Is that so?" So 'e says "Ye'h it is, it's down M Road as far as I know, an' I can't tell you any more". So I says, "Well what do they do there?" An' 'e says "you can do anything there". That's' ow I first got to know about this place. The followin' mornin', taxi cem to pick me up.' \*

One member of the group, Jamie, maintains he was coerced into going to the centres by his probation officer on the basis that it would help 'straighten' him out, after his second criminal conviction. Others were advised to use the service on medical grounds. Three respondents clearly recalled their doctors and physiotherapists recommending day centre attendance as part of their rehabilitation after the onset of their respective impairments. However, one individual suffering from a degenerative hereditary disease, was presented with little alternative during his final year at school.

'Well me social worker cem to our' ouse right. Well first of all in March [1985], before I left school. ..., when I was 16, this woman cem, an 'ealth an' safety worker or som't like that, a fattish woman wi' blonde 'air, she drove round in a BMW right. She told me I didn't need to try to get a job right. 'Cos I 'adn't t' fix machinery or owt like that, 'cos o' me safety. Like at Remploy or on a YTS scheme OK. In August Karen [specialist social worker for the physically disabled at that time] cem, an' she said she was gonna tek me down the YTS. She told me if I didn't like it then I could come to a day centre. We went down this YTS place right, an' I didn't like it. '\* -Billy

Up to this point Billy had led a relatively normal life, despite the fact that he had been diagnosed as having Freidrich's ataxia. He had attended a normal comprehensive school, knew little of his disease -neither its name nor its degenerative nature -and had experienced few visible symptoms other than an occasional loss of balance.

While Jamie and those directed into the system on medical grounds felt they had little real choice as to whether they should begin using the service, at least they had some inkling of why they were there. This was not the case for Wendy and Paul. Both said they were directed into the system after one year of further education by college staff, without any alternative being offered and with no explanation.<sup>2</sup> Paul stated,

'Graham, careers tutor at college, 'e cem up to me an 'e says "I think I've got somethin' for you", meanin' 'e's got some kind 'O place right, on a YTS or somat. An' I got all excited an every thin'. So I says 'Where is it?' An 'e says "It's Alf Morris day centre". An' me face dropped. ...Like we'd been round it at school an' I didn't think much of it then. ...An' 'e just says, "'When do you ;'ant to

start"? An' I didn't know what to say So I just says, "Monday?" I 'ad a week off from college, an' that were it.'\*

These placements were surprising since neither Paul nor Wendy suffered from a degenerative illness. They were both relatively moderately impaired when compared to others who had remained on the course for two years, but both had difficulty with basic literacy and numeracy skills. According to Jayne, they were referred to Contact simply because college staff felt that neither would benefit from another year in further education and there was nowhere else for them to go.

Despite the fact that all the users were aware that their continued attendance was voluntary, many felt they were presented with little alternative once their education ceased. Although conscious of the unemployment situation generally, they felt that the specialist careers services were at fault. In particular, they had been presented with inadequate information regarding other options and claimed they received no practical help in finding a job. This seems to be a common complaint among most young people with special needs who do not, on the whole, find contact with careers services very helpful (Parker, 1984). It is not surprising therefore that a substantial number were deeply unhappy about their present situation.

Three main reasons emerge as to why the majority of users sampled began using day centres. Firstly, some saw the centres as an opportunity to maintain long-established peer group contacts. This is an important consideration for all adolescents (Brake, 1980), but particularly so for individuals like those who, due to their restricted physical mobility as well as educational and social disadvantage had few social contacts outside school and were almost certainly aware that making new ones would be difficult. This is a common concern for many young people with physical impairments (Anderson and Clarke, 1982). Secondly, others, acutely conscious of the stigma attached to day centres and those who used them, viewed attendance as the only alternative to the debilitating psychological effects of the social isolation they encountered in the post-education year. Thirdly, some, mainly the adventitiously impaired, believed they were channelled into the system to aid their rehabilitation.

While this evidence clearly demonstrates the influence of professionals with regard to shaping the futures of young people with impairments, it also underlines the extreme lack of economic and social opportunities available to these individuals once formal education concludes. Moreover, although

some criticism may be levelled at professionals for introducing people to the day centre environment at such a relatively young age (particularly since many are likely to be susceptible to professional guidance, if only because of their previous experiences, and day centre attendance is normally seen, by both the general public and many day centre users, as the last option) any censures against these workers must be set within the context of restricted opportunities.

### User Interactions within the" Context of the Contact Group

There were four main user subdivisions within Contact which were differentiated by the degree of impairment and perceived dependence. Among these subdivisions were two friendship groupings, cliques or subcultures. The term subculture is used here to refer to the

accumulated meanings and means of expression through which groups in subordinate structural positions have attempted to negotiate or oppose the dominant meaning system. They therefore provide a pool of available symbolic resources which particular individuals or groups can draw on in their attempt to make sense of their own specific situation and construct a viable identity (Murdock, 1974, quoted in Brake, 1980, p.63).

One of these friendship groupings was characterized by its members' homogeneity in terms of physical impairments, long-established relations and affective interactions, and the other is distinguished mainly by its members' autonomy. These two cliques were characterized by opposing perceptions of dependence and day centre attendance, a disparity explained with reference to the degree of impairment experienced by the principal clique members and by their socialization. The remaining two subdivisions were less cohesive and exhibited less internal homogeneity. For neither would be designation 'subculture' seem appropriate yet they were distinguishable from one another and from those two subdivisions which coalesced as cliques. None of the various subdivisions was determined by gender, although sex-related behaviour was clearly evident in each of the groups observed.

The four subdivisions will be discussed sequentially with reference to the generally perceived level of physical impairment, the more severely physically impaired coming first. Although it is accepted that all organizations, regardless of size, will have an informal hierarchy

(Hargreaves, 1975) the order of presentation is not intended to imply anything about status position in any such hierarchy. While some of the members of the fourth grouping identified were accorded the highest regard by many users, and to some degree by the staff, because of their relative autonomy outside the day centres, this did not apply to all. The question of informal hierarchy is further complicated by the severity and nature of impairment. For example, individuals from both the first and third subdivisions were universally held in high esteem, but excluded from a great deal of informal social activity because of their physical limitations.

In focusing on informal interactions within Contact, it is important to emphasize that user behaviour was variously constrained by environmental features characterizing the three day centres. Intra-group cleavages were almost impossible to detect, for example, at the Engineers' centre where users' movements and interactions were controlled by both the environment and the type of activities provided. The following evidence, unless otherwise stated, is for this reason taken from the observed interactions at the Alf Morris and Dortmund Square units.

The first subdivision, subgroup A, included five users who were the most severely physically, and in one case psychologically, impaired people in the Contact group. They were Alison and Michael (two of the users I was unable to interview), Tony, Charles and Robert. Unlike many 'blind' people, Robert had no confidence whatsoever and would seldom move without assistance from staff after arriving at the centres. He attributed this to the psychological impact of losing his sight. Because of their impairments, all five were generally 'parked' on their arrival at the central tables in the main room at Alf Morris, or at a convenient table at Dortmund Square, where they remained for most of the day unless they had a social services' lunch which had to be taken in the dining hall. They were normally excluded from most informal user activity which tended to go on around them. Although interaction with other users did occur, this was usually only when little else was going on, or with one of the others who had only weak subgroup affiliations, such as Richard or Amy, both of whom were reputed to suffer from 'behavioural' difficulties and were accorded low status by the rest of the group.

These five people were frequently the primary focus of attention for staff both with respect to physical tending and social activity. All apart from Robert needed help with the toilet, although Charles was one of those people who never used it while in the centres. All five were viewed with varying degrees of sympathy by the rest of the users and were considered

a high priority for staff / user interaction by all Contact personnel, although like the users some of the care assistants (CAs)

*Table 15 Observed subdivision among Contact Users during Participant observation*

Name	Age when started using Contact (years)	Length of attendance (1.1.87) (years)	Weekly attendance (days)	Use of transport	Subgroup location
Margaret	18	5	5	yes	B
Tony	16	2	5	-	A
Joyce	18	3*	3	-	D
Billy	16	1.5	5	-	D
Andy	21	6*	3	no	D
John	19	1	3	yes	C
Sheila	19	0.5	5	yes	C
Jamie	18	6*	3	no	D
Sally	16	3	5	yes	B
Karen	17	1	3	-	C
Molly	19	6*	2	no	D
Matthew	21	3	4	yes	D
Paul	18	05.	3	-	C
Gavin	16	3	5	-	C
Norman	16	6	5	-	B
Barry	17	1.5	3	-	C
James	20	1.5*	3	-	B
Henry	18	2	3	-	C
Marilyn	19	5	3	-	D
Bruce	17	3	3	-	C
Nancy	18	2	3	-	C
Angela	16	5	5	-	B
Millie	16	5	5	-	B
Richard	17	3*	5	-	C
Wendy	17	1	3	-	C
Curt	16	5	3	-	B
Roger	25	5	3	-	D
Elizabeth	18	5	5	-	C
Charles	24	3	3	-	A
Spike	18	2	3	no	D
Philip	18	4	2	-	D
Robert	23	3	3	yes	A
Clive	20	0.5	2	-	C

Key

\*= attendance broken for more than one month when user left Contact to pursue other activities.

Source: user interviews, Contact register and field notes

interviewed displayed any coherent perception of the centres or of the other users. Charles viewed his attendance and his interactions with the rest of the group as essential for his 'complete recovery'.\* He felt empathy with the other users because as far as he was concerned they were in the 'same boat' as him. Tony, the youngest of the five, saw the centres as a 'doss place' where people only came to 'mess about'. \* He had no particular friends in the group but still enjoyed coming. Robert, in contrast, was compelled to use the system by his parents and admitted he would stay at home if given the opportunity. He had no friends in the centres other than Sean, the VW who replaced Pete as the group's male CA.

The second subdivision, subgroup B, were easily the most visible and the most cliquish in terms of close personal relationships. The social bonds-between members were based on homogeneity, in terms of both appearance and attitude, longevity, regular interaction and emotional involvement. It was also a relatively small association. It has been shown that personal relations between primary group members are likely to be stronger the smaller the groups are, the longer established they are, the more frequently members interact and the more homogeneous they are (Bulmer, 1987). All of these considerations were applicable to subgroup B. Everyone in it was born with spina bifida and hydrocephalus, although it is unlikely they were aware of this fact since they knew little of their conditions. They were all confined to wheelchairs and had been all their lives. All were doubly incontinent although not all sought assistance. In addition, apart from Curt, they were all relatively small in stature. They had all known each other since primary school and, with the exception of James, had attended Christy Brown school for their entire pre-16 education. James had also attended this school but left at 14 when his parents insisted he go to a local comprehensive. None of the seven group members, Margaret, Sally, Norman, Angela, Millie, Curt and James, had been separated from their parents for more than two weeks and none of them had ever had a job. The oldest of the group was 23 and the youngest 19.

They were easily distinguishable from the rest of Contact because they were rarely apart. Invariably they would sit together chatting or listening to music on one of their own portable radios or tape machines, usually away from the rest of the group. At Alf Morris this would be outside the main rooms used by the group, either in the cookery room or one of the side rooms if they were vacant, or outside if the weather permitted. At the

Engineers' and Dortmund Square, James and Curt were conspicuous by their absence since neither liked the atmosphere or the activities at these units. Sometimes at Alf Morris, Norman or James would join in formal group activities, if staff were involved. In this case the girls would adjourn to the large waiting area inside or immediately outside the ladies' loo.

Although they all wore reasonably smart clothes, none was overtly fashionable. Part of the reason for this lies in the fact that people with impairments often have difficulty finding clothes which fit. It was apparent that their wardrobes were chosen for their utility, and by their parents. Their interests were similar to those of working-class youth generally, revolving around leisure, peer groups and, to a lesser degree, style (Brake, 1980). Their relative lack of enthusiasm for the latter is likely to be due to the fact that they were unable to wear overtly stylish clothes. Their conversation was generally lightweight, covering day centre gossip, the previous night's TV programmes, mainstream pop music, the type of music they listened to, and their personal relationships.

The only lasting personal relationship in Contact was within this subgroup. Norman and Angela had been engaged for over two years, although neither appeared to take the relationship seriously in the conventional sense. When asked if they intended to marry Angela would shrug and simply say she had no idea and it was up to Norman. For his part, he said he was not interested in marriage because he intended to stay with his 'mam'. Apart from their liaisons at the day centres, which usually meant Norman leaning on Angela and feigning sleep, their only other contact was at the Physically Handicapped and Able-Bodied (PHAB) club or when they went out with their families, who were neighbours, had known each other since their offspring's childhood and also frequented the same social club on Saturday nights.

Other relationships within this group were extremely transient, often lasting no more than a day. For example, one day Millie would declare with complete confidence and sincerity that she was 'going out' with one of the others in the group or that she had a new boyfriend. The next day the romance would be off with little apparent regret. Personal relationships were discussed with an air of naivety appropriate to much younger individuals. They were generally interpreted as an indication of childishness by several of the other users and the majority of staff. Often the CAs were discussed in this light, but no attempt at contact or approach was ever made. As one female CA put it,

'It's just like little kids, it's just like they're playin' at bein' grown up. I don't think any of them have had a proper boyfriend. .., or girlfriend. It's all in their minds, it's just somethin' to talk about'.\* - Maria

The staff generally viewed this group as relatively immature for their years. This is often said of young people with impairments. Anderson and Clarke (1982), for example, point out that 'handicapped youngsters' are more likely to be functioning in terms of social and emotional maturity at a level two or three years below that of their peers, particularly if they have been educated in special schools. While social interaction between staff and this group of users did occur it was usually on a formal basis. While they were all dependent on staff for toileting, they approached these interactions in a matter-of-fact fashion which conveyed little if any embarrassment. They also took the most positive view of the day centres of any of the users. At the start of our formal interview Norman said,

'I don't want you to say owt' bad about this place ... , cos' I like it 'ere.' \*

A female member of the group stated,

'I think it's great 'ere, I'd come on Saturdays an' Sundays if they were open.'\* - Millie

All spoke of others in the clique as best friends. And while it is often stated that most informal friendship groupings have a leader (Hargreaves, 1975) none was obvious, although it may be that this role fell to Norman, because of his seniority in Contact generally and the fact that he was the only male in this grouping who used the centres every day of the week. All said they got on relatively well with the majority of other users, but some animosity was expressed toward the rowdier elements in Contact, notably Andy, Billy, Jamie and Spike, because they were occasionally disruptive and abusive towards them. In short, these users were by far the most consistent and well-adjusted members of the Contact group. Since they appeared to accept their dependent status with little difficulty I shall refer to them as the 'conformists'. They were relatively autonomous within the confines of the day centres, rarely showing any visible signs of emotional upset or depression, unlike some of the individuals in the two subdivisions discussed below.

The largest subdivision in the Contact group, subgroup C, numbering thirteen in all, had no visible subgroup affiliations. They suffered from a farrago of conditions ranging from muscular dystrophy to 'behavioural' problems. Only John, Gavin and Bruce were permanently confined to wheelchairs. All three had walked when they were younger. The remainder were all ambulatory, although four, Sheila, Karen, Barry and Elizabeth, used chairs when not in the centres. Five had experienced education in normal schools before the age of 11, but while Karen, Nancy, Wendy and Richard had all hated it, because of the bullying, John, who had been able-bodied before his accident and had been sent to a secondary remedial school because of his learning difficulties, told me,

'T' school were all reet, Igor' on wi' other kids an' that. It were just that I wa'nt any good at readin'.'\*

Although in this grouping only Sheila had any academic qualifications and some could be regarded as 'slow' in certain areas, particularly literacy and numeracy, this should not be construed as an indication of the group's intellectual dullness. Gavin, for example was generally perceived as one of the brightest boys in the entire group. He and Elizabeth, who was one of his regular companions, often sat working through the computer instruction manual without help. Another boy from this faction, Bruce, despite a limited education owing to having spent much time in hospital, had an encyclopaedic knowledge of sport, especially football.

This was not applicable for others in this group, however. Barry for instance was regarded by everyone as a 'bit thick'. He was inseparable from his best friend, Henry, who took it upon himself 'to look after him'.\* Henry was bright but extremely shy, preferring to stay in the background. According to senior staff, self-confidence had never been his strong point, but what little he had had been further undermined in 1985 when he was hit by a car while crossing the road. Karen had a similar disposition, and was drawn to socializing with the girls in the 'conformist' group but was frequently upset after these interactions, because she felt they put on her by asking her to fetch things for them, such as tea or coffee. She also had a chronic affection for James, which was seldom reciprocated and this only added to her general depression. Others in this group were prone to similar moods. Wendy was regularly distraught due to her living accommodation. Amy and Richard were similarly affected because they were nearly always excluded from informal user activities due to their 'babyish' ways. Both were subject to violent mood changes and would cry or sulk for long periods. On occasions *this* would mean sitting alone with their head bowed for five to

sixty-five minutes, speaking to no one until one of the staff took an interest. Amy was also diagnosed as an epileptic and would frequently have one or more seizures after heightened activity or successive mood changes. When excluded from all other social activity, both Amy and Richard sought out the most severely impaired Contact members, particularly the three who were unable to talk. This provided them with both companionship and usually a positive response from one of the staff.

Those in the third subdivision rarely ventured out of the main Contact areas, nor out of earshot of senior staff. Wendy, for example, could normally be found sitting next to Jayne or Jackie. In terms of physical appearance, none of them wore 'trendy' clothes. In fact some were quite poorly dressed. By coincidence, this was a reflection of the fact that most were reputedly from the poorest families in the group. In many respects they were not as physically impaired as others in Contact, but in many ways they demanded a higher degree of attention from staff, who, in general, looked upon them as victims, not fully responsible for their predicament or their behaviour. In return many of them viewed staff in an almost deferential light. Elizabeth for example said,

'I don't know where we'd be without 'em. You've got to 'ave staff in case you get stuck or owt, say if you fell...., where'd we be then ...'\*

Like subgroup B most of this group took a fairly positive view of day centre attendance, notwithstanding that Karen and Wendy claimed they would prefer to do something else, though neither knew what. Apart from Barry and Henry, none had any particular friends. They were the misfits, the floaters and the loners. Sometimes they were included in social interaction with others in the group. Clive, for example, would sometimes be found with the conformists and Sheila with the girls in subgroup D. On other occasions they were ignored. They were the 'silent majority' occupying the middle ground between the groups mentioned earlier and the remaining subdivision described below.

Those in the final subdivision, subgroup D, were distinguishable by their relative maturity and autonomy, both inside and outside the centres. As a result they were often less visible than the other subdivisions but were characterized by the similarity of their attitudes to the other users, the staff and the centres generally. Included in this grouping were the five who did not use social services' transport and therefore attended as and when they felt like it. This could be anything from three or four times a week on a

regular basis in the winter to once a fortnight in the summer. This group included Joyce and Marilyn who only visited the centres in the afternoons, as well as Roger who was the oldest user in Contact and Billy who was the youngest. They were generally the least physically impaired.

All were ambulatory in the centres, although Billy and Joyce occasionally used wheelchairs outside.<sup>4</sup> Three of the group were adventitiously impaired and like Billy and Matthew had gone through normal education without interruption. With the exception of Molly, who was one of the least impaired users in the centres, all the congenitally impaired individuals in this faction had been separated for long periods from the parental home either through attending boarding school or residential colleges. All bar Jamie and Spike, who were by no means unintelligent, had some academic qualifications. And several had spent lengthy periods outside the centres either at college, on government-sponsored youth training schemes (YTS), or in work. This group also includes those people who had set up homes of their own as well as Spike and Roger, who had both left home before the advent of their impairments, Spike to join the army and Roger because he could not get on with his family.

Because of their relative autonomy, associations between members of this subdivision could take many forms, but when inside the centres they generally congregated together and away from the majority of Contact users, usually at the far end of the smaller of the two rooms at Alf Morris, or in the library at Dortmund Square. If several were sitting around a table and someone arrived who was considered part of the group, then a space would automatically be made for them, while the arrival of non-members would be ignored. These congregations normally only took place in the afternoon, because some of the principal members did not arrive until then. They would usually include one or two of the CAs, Pete, sometimes Annie, work permitting, and two of the female voluntary workers (VWs). This meant that on occasion some of these workers spent a disproportionate amount of time with this subgroup. If only a few of the group were present, then some of them would disperse to other parts of the centre and interact with other users or, more often than not, with staff. Matthew, for example, would regularly play dominoes in the lower building at Alf Morris with some of the older users and the male CAs. Philip often sat chatting to Bob, the activity organizer (AO) in charge of the carpentry workshop; and Joyce, Molly and Marilyn could be found talking with Eileen, the centre's hairdresser.

These individuals were also distinguishable from the others in Contact in their appearance. Unlike those discussed above, who had obviously been 'got ready' by someone else, they were clearly concerned about the way they looked, and wore clothes and make-up similar to those worn by their able-bodied peers. Billy wore sports shirts, jeans and trainers, Jamie sported a skinhead-style haircut and Spike draped himself in a black leather jacket covered in studs and the names of heavy rock bands. Philip, who was married, usually turned up in jeans, jumper and anorak, like most able-bodied young married men out at work. The girls in the subgroup were extremely fashion-conscious and took meticulous care over their clothes, make-up and hairstyles. Informal group discussions covered essentially the same topics as those of subgroup B, namely, leisure, peers and style, although gender differences were more prevalent. In addition, there was a definite tendency among the males toward the macho values generally associated with working-class youth subcultures. Conversations usually revolved around music, the opposite sex, "avin' a laff" and, when the girls were not present, violence and fighting (Hargreaves, 1967; Willis, 1977; and Brake, 1980).

Compared to those in the other subdivisions in Contact, however, they were far more discerning in their tastes. For example, a common topic of conversation for the 'lads' was the merits of particular heavy rock bands, a subject especially close to the hearts of Billy, Roger, Spike and Pete. The girls talked about individual rock stars. Mainstream top ten 'pop' was usually dismissed as 'rubbish'. Sex was frequently a subject for discussion, but it was talked about in a far more worldly manner. When the girls were not there the lads' conversation often turned to the physical attributes of the female day centre staff, particularly the young CAs, or sometimes Marilyn, who was generally regarded as the most attractive girl in the group, the day's page three girls, their sexual fantasies and their exploits; It was clear from the tone of these conversations that their (sexual) activities were not limited to fantasy. During this study Jamie experienced fatherhood and Spike and Billy both asked a number of the young CAs and Marilyn out. And Barbara, the 17-year-old VW, went out with Billy for six weeks.

When the girls were discussing this topic, they took a more moral approach (at least in my presence) emphasizing the virtues of chastity before marriage. Although they did discuss men in a similar vein to the lads, arguing for instance over their looks, they never spoke of other users or people who worked in the centres in this light. All the girls were adamant that they would never go out with anyone who was 'handicapped'. Marilyn,

for example, only had eyes for one of the taxi drivers who she thought looked like Rod Stewart, a rock star.

Usually', avin' a laff' meant relating past experiences, discussing their social lives outside the centres, moaning about the day centres and 'takin' the piss' out of some of the staff, usually senior personnel outside Contact, and other users, including the elderly and some Contact members. These conversations, however, rarely went outside the subgroup. It was unusual for any of them to ridicule anyone openly.

The four most dominant lads in the group, Billy, Andy, Spike and Jamie, adopted what has been termed a 'delinquent orientation' (Hargreaves, 1975) or an overtly rebellious stance against formal authority. They often talked about violence, martial arts and their ability to fight. Sometimes these conversations erupted into displays of aggression and occasionally fights, usually over who was the " ardest", although these conflicts rarely went beyond pushing each other around. The ability to 'stick up for yourself' was important to all four. When these discussions got out of hand or attracted the attention of senior staff, other subgroup members, both males and females, normally moved away.

A general antipathy toward several of the other users in Contact was common to all in this faction. While individuals such as Charles or Gavin, whose physical impairments were judged severe, were accorded a great deal of sympathy and occasionally inclusion in group activity, others considered 'a bit mental' such as Amy and Richard and the 'conformists' group were viewed with universal disdain, both for their immaturity and perceived passivity. Billy, for example, who was only 17 himself, told me repeatedly how the others in the group,

'especially them in wheelchairs mek' me bleedin' sick. For most of 'em it's like they're 2 year old, you know what I mean. It's like they've never grown up, they want to be carried around like babies.'\*

Many of the individuals in this faction experienced sporadic bouts of depression stemming directly or indirectly from their impairments. Billy was deeply upset by the fact that since leaving school he had lost all his able-bodied friends. Roger was constantly at odds with his family and desperately wanted to leave home. Throughout the study Philip was having marital difficulties and some of the girls were prone to periods of acute anxiety over their 'spoiled body image', a common concern for impaired

women (Campling, 1979). Joyce, for example, would never have her photograph taken unless she was sitting down or when her lower half was out of camera shot. Because they discussed these experiences with senior and junior staff, both professionally and socially, it stimulated a higher level of empathy between staff and them, as opposed to others in Contact. This was apparent in both casual conversation with staff and in their interviews.

Adolescent traumas are exacerbated by disability for all of them, fitting into a peer group, fashion, all the things that are important to all teenagers, they're all exposed to them, especially after coming out of special education and back into the community. ...But for some, if they're born with it, there's a kind of an acceptance of the disability and its limitations. There's a realization that they're different but I don't believe it's as profound for them as it is for. ..say Billy or Spike.' \* - Jackie

Although interaction with staff was important to this group it did not alter their ambivalent view of Contact and the centres in general. All confessed to using the system because they felt they had no choice. These views were best summed up by Joyce when she was discussing her return after her two years at an able-bodied college.

'Well you get in like a Catch 22 situation. I was determined not to come back after I'd left college, but you get. .., you know, you get so down. When the holidays' ave passed an' you're still sat there, an' you get so bad you can't even be bothered to answer the phone when somebody rings- up. It gets that bad you can't be bothered to push yourself to do 'owt. Put it this way, if I 'adn't come back I'd 'ave gone off me 'ead.'\*

Each of this subgroup's members nominated others in the group as friends, and all said it was unlikely they would use the service if the others did not attend, In terms of popularity, or 'sociometric status', Marilyn was by far the most popular girl in the group, due largely to her physical attractiveness, She received attention from males, both users and staff, which in turn attracted the females, Her sociability and her independence outside the centres, which provided constant new conversation topics, also added to her popularity. In addition, she was a regular attender.

Because some of the lads were frequently absent, it was difficult to assess who was the most popular and influential among them. If, for example, someone was missing for a while then they were automatically the focus of attention when th~y returned, since they usually had much to talk about.

Although Jamie was held in high esteem by all the males because of his past (he had two convictions for assault), his independence, and his extrovert personality, he was not as popular as Billy. While both were often at the hub of group activity, due to their ability to make the others laugh by acting the clown or 'messin' about', Billy had the edge because of his youth and freshness. These attributes are valued by most individuals, impaired or otherwise.

While explanations for the behaviour patterns of the first and third subdivisions can only be drawn satisfactorily with reference to individual life histories and subjective physical and psychological impairments, an explanation for those of the second and fourth subgroups can be found by referring to two distinct but related factors. These are (a) the degree of impairment and (b) socialization. In relation to impairments, subgroup B were all similarly disadvantaged, both in terms of cause and degree. When compared with others in Contact, excluding those in subgroup A and some from subgroup C, such as Gavin, their impairments were relatively severe, particularly with regard to mobility. In contrast, those in subgroup D were the least overtly impaired, albeit their impairments were diverse. In view of the general tendency for like-situated individuals to identify with each other, a tendency which is particularly acute during adolescence, this pattern of 'in-group alignment' (Goffman, 1968) almost inevitable.

Further explanations for these affiliations may be found with reference to users' life experiences prior to this study. This is especially important since others in Contact were similarly impaired, but not normally included in either of the two principal friendship cliques. Consequently explanations which rely on impairment alone may be considered inadequate.

Most of the members of subgroup B had remarkably similar biographies before their introduction into the day centres. Their dependent status had been learned through sustained interactions with their families, professionals, teachers and, most importantly, with each other. They had literally been socialized into a culture of dependence since they were born. For them dependence was normal and apparently not considered a major problem. Their transition to day centre user status was merely another stage in the continuum of their dependent career. Subgroup D, on the other hand, was composed of individuals who had either (a) spent long periods away from the family home in residential schools or colleges and *for* been partially integrated into able-bodied society, as in the case of the congenitally impaired, or (b) been part of that society before impairment, as in the case of the adventitiously impaired. Normality for them was able-

bodied normality, not dependence. Moreover, since the norms and values of this grouping were similar to those of non-impaired working-class youth subcultures generally, especially those in state comprehensive schools, there is an element of continuity here also. Additionally, since gender roles are particularly significant in these subcultures this may explain why gender-related behaviour within this subgroup was more pronounced than in the others discussed. While the cultural values of the conformists may represent a form of resistance to the negative perceptions generally associated with disability, those of subgroup D are clearly a form of resistance to the imposition of the disability label.

With regard to the reference groups, distinctions can be made between (a) the group of which an individual is a member for social categorization, such as the disabled, (b) the group whose norms and values the individual accepts, and (c) the group of which s/he is not a part but to which s/he would like to belong (Hargreaves, 1975). While the principal reference group for the conformists was each other, or the disabled, the primary reference group for subgroup D was the able-bodied. While subgroup B adjusted to day centre life with relative ease, subgroup D adjusted to it with reluctance. As a result the latter had generally devalued conceptions of self and were prone to the type of severe adjustment difficulties generally associated with coming to terms with a disabled identity during adolescence, hence their animosity toward other users, particularly those who represented for them the disabled stereotype, their affinity with some day centre personnel and their ambivalent attitude toward the day centre system as a whole.

With reference to Goffman's (1968) analysis of coming to terms with a devalued or disabled identity, the pattern of socialization experienced by subgroup B conforms to the first model identified, which suggests individuals with congenital impairments can be socialized into accepting a disadvantaged status during childhood, while the previous life experiences of the individuals in subgroup D were broadly comparable to the second, in the case of the congenitally impaired, and the third, in the case of those with acquired impairments. His second model concerns those similarly impaired but who are unaware of their disadvantaged position until later in life. The third relates to the adventitiously disabled and the re-appraisal of self after the onset of impairment.

The data in this section have shown that there were four distinct informal user subdivisions within the Contact framework. The first, due to the severity of their impairments, was dependent almost exclusively on staff,

both for physical tending and social activity. The second was a distinct subgroup or clique, with its own values, culture and structure. This group conformed in many ways to the general view of the disabled and its members had normalized their dependent status. They took a positive view of staff, on whom they were dependent only for physical tending, since social support was provided by others in the group, the day centres and the majority of other users. The third subdivision was conspicuous by its lack of cohesion. Its members had no definite subgroup affiliations but innovated and adapted as the need arose. Although the majority were less physically dependent on staff than the others mentioned, several required higher levels of social support. The fourth subdivision was distinguishable from the others by its members' physical independence and relative maturity, both inside and outside the centres. Like the second grouping they had their own values, subculture and structure, but unlike subgroup B and the majority of other users, they had difficulty accepting the consequences of their impairments, namely, the dependent status. They therefore disassociated themselves whenever possible from those in Contact who appeared to accept the system without difficulty. Consequently, although they derived social support from each other, they were disproportionately dependent on staff for this function. They viewed the Contact group and the day centres with ambivalence. For them, the ritual of attendance was due to necessity rather than choice. These apparent differences were explained with reference to two distinct but related factors, namely, the degree of impairment and differential socialization.

These findings, particularly the dimensions and severity of impairment, the differential orientation toward self and others, and the tendency toward factionalism among Contact members, might help to explain why senior staff adopted policies of 'enlightened guardianship' which attempt to accommodate both the dependent and the not so dependent. If these findings are representative of young people with impairments in day centres and other institutional settings, and I believe they are, then they may also explain why there is still a prevalence of this policy in social provision generally, especially that which is aimed at this particular user group.

## Conclusion

This chapter has looked at the individuals who constituted the Contact group. The evidence shows that although there was a high degree of homogeneity among Contact members with regard to cause and type of impairment, previous experience, economic and social disadvantage, which

subsequently led to their day centre attendance, this homogeneity did not extend to their attitudes relating to their dependent status, day centre staff, and the service generally.

The data show that the overwhelming majority of users were from the manual working classes and the majority grew up in economically and/ or socially disadvantaged households. Although there was some diversity in cause and severity of impairment among users, most were congenitally impaired and mobility was a major problem for the majority. There was a general lack of knowledge among respondents about their conditions. Many had spent long periods in segregated institutions such as hospitals, special day schools, and residential schools. Those who attended residential schools viewed the experience positively in relation to furthering their independence. Over half the congenitally impaired respondents had been on vocational/independence courses in colleges of further education and three had integrated into schemes for the non-impaired. Their efforts with regards to finding paid employment proved fruitless. Work experience among those impaired at 16 was conspicuous by its absence. None of those with acquired disabilities had ever been unemployed before the onset of their impairment. All the respondents were economically dependent upon the state and only five were independent from their families in terms of accommodation. Of these, two were living in residential institutions. In conjunction with other studies in this area, the data in this section underpin the general inadequacy of some forms of special education and the poverty of economic and social opportunities available to young people with impairments during adolescence.

Although unemployment is a tacit factor, three main reasons accounted for users joining the Contact group. Some apparently wanted to maintain long-established peer group relations. Others, although aware of the stigma attached to day centres, viewed attendance as preferable to the extreme social isolation encountered in the post-education period. The remainder, mainly the adventitiously impaired, believed it would assist in their rehabilitation. The data brought into focus the severity of the social isolation these users experienced in the post-education years, a problem which is common to many young people with impairments, and it showed how influential professionals were with regard to shaping their lives. I noted here that any criticisms directed at those responsible for introducing Contact members into the day centres should be set within this context.

The final section discussed the four principal subdivisions within the Contact user body as differentiated by degree of impairment and perceived

dependence. Among these subdivisions were two friendship groups or cliques with apparently contradictory perceptions of dependence, day centre staff and the day centres generally. These attitudinal differences were explained partly with reference to the degree of impairment but also as a consequence of differential socialization of group members. I suggested that these contradictions may go some way in explaining why 'enlightened guardianship' was the management strategy adopted by Contact staff. Similar attitudinal differences were also evident in users' views regarding user participation and control within the Contact group. These subjects are discussed in detail in the ensuing chapter.

## Notes

- 1 The Family Fund is a government fund administered by the Joseph Rowntree Memorial Trust for families caring for children with impairments whose needs fall outside statutory provision (Bradshaw, 1980).
- 2 Both Wendy and Paul were enrolled on the independence course for students with special needs which lasted one or two years depending on college staff's perceptions of need.
- 3 Margaret and Angela had both stayed in residential homes while their respective families had gone on holiday.
- 4 As his illness grew worse, Billy's use of a wheelchair increased steadily throughout the study period.