

### **Chapter 3 (In 'Cabbage Syndrome': The social construction of dependence, Colin Barnes (1990) The Falmer Press, pp. 40-55)**

#### Methodology

'Methodology' is a more or less systematic or organized way of acting. An account of one's methodology must therefore include a statement of one's intentions or aims. Aims, however, can only be defined in the context of some conception of the nature of the problem at hand, or of some 'theory', Method, then embodies theory, and doing 'research' is not discovering new phenomenon but recovering what one had all along (Blum, 1970, p. 305).

When confronted with the obligatory chapter on research methods many social researchers seem to opt for a succinct but revealing autobiographical account of how and why their interest in the subject arose and how it affected their investigation (Bell and Newby, 1980). The following pages will broadly follow this tried and reliable formula. The initial aim is to outline the main reasons for my interest in disability generally and the interactions between the helper and the helped within the day centre environment in particular, as well as the considerations which prompted the conceptual approach. A further intention is to discuss the reasons for, and the choice of, the strategies employed in pursuit of those objectives. Thirdly, I will briefly chronicle how those strategies were put into practice in terms of setting up the study, the choice of location, samples, interview schedules and data collection. And finally, some of the principal methodological difficulties which occurred during the study will be examined.

#### Personal Biography

My initial interest in disability stems from personal experience. I was born with a hereditary eye disease and spent the first seven of my statutory school years in 'special' education, firstly in a residential institution for the blind and deaf and later in a school for the partially sighted. Indeed, had it not been for my mother, who persistently badgered the local education department with the request that 'I should go to an ordinary school like everybody else', it is highly likely that I would have remained there until leaving school, at which time, no doubt, I would have been directed toward 'sheltered' employment, like most of my junior school peers and my father before me. In the event I ended up with a relatively average education and an active social conscience. After several years in the hotel and catering industry I became interested in the problems associated with disability

when I decided to become a teacher. At teacher training college I was disturbed by the remarkable lack of literature dealing with the meaning of disability. This was particularly alarming considering this was in 1981 -the International Year for Disabled People. I was subsequently advised by one of my tutors to look to sociology for explanations for this sorry state of affairs.

After studying many of the major works which constitute the bulk of undergraduate sociology courses I was still struck by the paucity of references concerning impairment and disability. Further research, however, revealed that the situation was not as bleak as it seemed. But like many of the authors studied, particularly those who were impaired themselves, I was unhappy with both the prevailing functionalist and interactionist approaches to this subject. The limitations of the sick role, the rigidity of its subsequent variations and the emphasis on individual responsibility for explaining the difficulties experienced by people with impairments were particular weaknesses associated with functionalism. The discovery of the work of the labelling theorists reaffirmed my belief that many of the problems associated with impairment were socially created, but offered little in terms of an explanation for the multiple economic and social disadvantages that many encounter. Hence I was drawn toward a more historically based, radical analysis currently referred to as 'social oppression theory'. Although I broadly accepted its central tenets, that impairment and disability are socially created and that much of traditional and present social policy can best be understood with reference to mechanisms of social regulation and control, I was less content with its analysis of the helper/helped relationship, particularly within the context of day centres for the younger physically impaired.

My interest in day centres again stems from personal experience. While at university I worked as a voluntary worker in three local day centres with a group of young adults with physical impairments. And although some of the general criticisms levelled at day centres (discussed in Chapter Two) were applicable to these services, others were not. For example, the centres were overtly segregative, all the users were impaired, the vast majority were elderly and many of the facilities offered were either inappropriate or inadequate for young people. However, censures regarding helper / helped interaction were less clear cut. At face value at least, the relations between the two were overtly positive. Moreover, it was my opinion that there was an empathy between many of the users and staff in the centres, and that the latter, rather than reinforce dependence actively sought to overcome it.

Moreover, since the formal mechanisms for user involvement in the running of the centres were relatively intact, although underused, I also had

misgivings concerning the assertion that most day centres were essentially paternalistic (Oliver, 1983a), so far as the latter is taken to mean the benevolent philosophy of 'parens patriae' which disguises the fact that people are seen as immature, unworldly and incapable of making decisions concerning their own welfare or future (Kittrie, 1971). There had been little evidence of the extremes of this ideology in the centres. Although the behaviour of some of the users could be construed as childish or naive, there were other individuals in the units, who exhibited none of these characteristics. In fact there were crucial differences within the user group in which I was interested, those aged between 16 and 30 years, in terms of the degree of impairment and attitude toward dependence and toward the day centres generally. While some appeared relatively satisfied with the service, others were less enthusiastic.

In view of the recent heightened interest in the general areas of disability and social policy by both policy-makers and theorists, these considerations stimulated a number of important questions. For example, why, given the obvious limitations of this system and the lack of overt coercion in recruitment of members, did people use it? Why was there so little visible user participation in the running of the service and why, given that some of the less overtly disabled users were clearly dissatisfied with the centres, did they continue to attend? In my attempt to answer these questions I hoped to fulfil two specific aims: (a) to provide a comprehensive insight into the daily interactions between users and between users and staff, and thus contribute to the knowledge of those who formulate policy in this area and (b) to add to the theoretical debate concerning helper/helped relations.

## Strategies

Since it is widely acknowledged (for example, Abberly, 1987; Hurst, 1984; Oliver, 1986) that interactionist methods are the most appropriate for studying the problems experienced by people with impairments, my choice of methodology appeared unproblematic. Like Goffman, Becker and countless other researchers before me, I would venture forth into 'the field' and take up the position of a participant observer, or to be more precise 'a complete participant' (Denzin, 1970). From the outset I intended to become a full time voluntary worker (VW) in the day centre system where I had previously worked. I felt secure in this choice of methodology as I was acutely aware of the major problems associated with this technique, but believed I was in a relatively strong position to overcome them.

According to a recent analysis by David Silverman (1985), there are several problems associated with this strategy. Firstly, the focus upon the present may preclude sensitivity to important events which occurred before

entry onto the scene. Secondly, informants may be entirely unrepresentative of the other less open participants. Thirdly, the observer may change the situation just by her/his presence, so the decision as to what role to adopt will be fateful. Finally, the researcher may 'go native' identifying so closely with the participants that 'like a child' s/he cannot remember how s/he found out, or will be unable to articulate the principles underlying what s/he is doing.

With regard to the first difficulty, I had been involved with this day centre system and the young impaired, on and off for four years, prior to the decision to enter as a researcher, and so had some knowledge of the situation applying earlier. The second point seemed similarly irrelevant in my case, largely because the work I had already done in the day centres meant that I knew the vast majority of users in the age group I was interested in and all of the staff.

Secure in these assumptions, I felt my intrusion into the day centre system on a full-time basis would be almost negligible, as it was precisely the position I had been in on several occasions in the past, notably during the long summer vacations while at university. Moreover, the role of VW in my estimation is an ideal role for the researcher within this type of environment since VW s are generally seen in a positive light by both users and staff. VWs are usually involved in social and/or didactic activities organized to provide psychological or social support for users. Consequently they are in a good position to 'talk' to both users and staff on a regular and fairly equal basis. They are not usually expected to perform physical tending tasks such as helping users with the toilet or bathing, although in practice I was often asked by both helpers and the helped to assist with the former due to the chronic shortage of male staff. The need for assistance with bathing does not often arise in relation to the younger impaired as most do not live alone and where necessary this function is performed by parents or guardians. With this in mind I was confident that my 'research stance', or the relationship the researcher has with her/his subjects and how it is linked to their attempts to grasp their own reality (West, 1979), was legitimate and defensible (from a 'researcher' point of view).

Although sympathetic to the central. argument of the proposed thesis, my supervisors were less convinced. 'How will your account be anything other than your own interpretations?' 'How will you be able to validate your findings?' I was asked, and initially I must confess my confidence was severely dented by these blunt enquiries which pointed out the flaws in my chosen methodology. Following Goffman' s study of a hospital for the mentally ill, I had originally planned to work in the centres for a year to accumulate the appropriate data. It was suggested, however, that I

supplement this technique-with a number of semi- structured interviews with a representative sample of users and staff. Although at first I was sceptical of this proposal, because of the positivist assumptions endemic to it (Silverman, 1985), on reflection it seemed like a good idea, since I was eager to make every effort to eliminate as much subjective bias as possible and keen to get on with it and 'tell it like it is'.

### Setting up the Study

Once the choice of methods had been established, the next stage involved getting formal permission from the local authority's Social Services Department for entry into the day centre system on a semi-formal basis, semi-formal in the sense that I would no longer be simply a volunteer but also someone conducting field research. The recent volume of criticism directed at welfare agencies in general, and government departments in particular, left me uncertain about the prospect of getting official approval of the project. I was patently aware that a major part of my function as a sociologist would be that of critic, and that in all probability those in the Department would be aware of this too, or if not, I would have to tell them.

Because of my previous experience within the centres I was reasonably confident about the reception of my proposed intervention by users and staff, believing that it would evoke indifference at worst, but at best, enthusiasm. On a number of occasions during casual conversation, several individuals, both users and staff, stated that there was a relative lack of knowledge and understanding of the experience of disability, especially of life in day centres, on the part of both the general public and staff in other agencies. At the same time students in the centres were not uncommon since a local college of further education sometimes places people on community care courses in them to gain practical experience. In any event, given the general view that there were never enough staff, I felt that the chance of an extra experienced VW on a full-time basis for up to a year would be welcomed.

Before contacting the central offices of the Social Services Department I thought it important to discuss the proposed project with the people who were to provide the data, those who use and work in the centres. The reasons were twofold. Firstly, if anyone in the units had any objections to the project then I felt they should have an opportunity to say so. In the event of any serious misgivings I would have felt obligated to find other venues for the study, or revise it substantially. As it turned out everyone viewed the idea enthusiastically.

I then forwarded a letter outlining my proposals to the appropriate departmental office, including a copy of the research draft that I had submitted to the University and the Economic and Social Research Council (ESRC) in order to secure financial support for the project. A week or so later I received a formal letter asking me to contact the Residential and Day Care Officer (RDCO) in charge of the provision for the physically impaired, Mrs B. I rang her office immediately and was asked to report for interview a week later.

I had not met Mrs B before, and anticipated all sorts of constraints and demands would be placed upon my activities in order to prevent any possibility of the research showing the Department in a poor light. I went to the interview as soberly dressed as I knew how, keen to explain my ideas and defend the professional integrity of the intended enterprise. The interview lasted an hour and three-quarters and was far less traumatic than I had originally envisaged. Mrs B requested that I specify in writing the principal reasons for my study, indicate how it would be conducted and state my intentions with regards to the conclusion. This I did, re-emphasizing that a synopsis of the research and its findings would be submitted to the Department, albeit without the inclusion of any of the names of individuals, whether users or staff, who contributed to the study. This was particularly important since it was likely that the completed draft would include subjects' quotations and therefore it was crucial that respondents' confidentiality should be protected. Mrs B listened intently and when I had finished proceeded to give me a detailed appraisal of the current day centre services for the physically impaired provided by the Local Authority, and the increasing financial pressures restricting their expansion.

Mrs B then stipulated three preconditions which I had to accept if the research was to proceed. The first was that if I should change my research design or proposed methodology I should inform the Department straight away. Secondly, if I intended to use any form of printed questionnaires, postal surveys or other written material which respondents would be expected to sign, I should submit them for official scrutiny and await approval before proceeding further. Finally, I should allow Mrs B to formally introduce me to the users and staff in each centre where the study was to take place. The purpose of the last point was to ensure that everyone in the units was fully aware that compliance in any interviews or structured conversations would be strictly voluntary and to satisfy herself that no one had any objections to the investigation.

I agreed but had misgivings concerning the last point since I felt that a formal introduction to people I already knew might backfire. I was

convinced that it would mean that I would be identified with the 'establishment' rather than as unattached observer. In the event, my fears were unfounded. After my 'presentation' by Mrs B to the people in the day centres, users and staff convinced me that the whole exercise was bureaucratic protocol and nothing more.

### The Choice of Location

After my official introduction into the service I set about reaffirming my knowledge of the service to be studied. It was confirmed that in the city where the study was situated the group in which I was interested were served by one organization only which was referred to as the 'Contact group' and operated in three different centres on different days of the week. The centres were known as 'The Alf Morris', 'The Engineers' and 'The Dortmund Square' day centres.

Officially the Contact group existed to cater for the needs of those in the 16-25 age group while another two user groups, both named 'Insight', provided services for people aged between 25 and 45. Closer inspection of the registers revealed that there were thirty-six Contact users with an average age of 22.5 years, but three were in fact over 25. This is the primary reason why the age boundaries for inclusion in this study are 16 to 30 rather than 16 to 25. Only one of the two insight groups had users in the required age range. This unit had a membership of ten but only three were between 25 and 30. The average age of the remainder was 40. Moreover, since there was relatively little helper/helped interaction within the Insight framework, apart from when users needed help with physical tending, I felt my time in the centres would be better spent with Contact.<sup>1</sup>

### The Sample

The criteria for inclusion of users in the study was fairly straightforward, namely, physically impaired regular day centre users within the designated age range. I decided to interview all those who qualified, making a total of thirty-six Contact members. This was deemed necessary because the number was a manageable one. However, as my knowledge of the limitations of 'representative samples' (Hughes, 1981) and because of the people in the group increased, it became clear this would not be possible. Two individuals eligible for inclusion, Michael and Alison,<sup>2</sup> were so severely impaired that coherent communication without the aid of a third party was impossible. Both had cerebral palsy and had hardly any recognizable vocal abilities. Indeed, I have never heard Michael utter a sound although I was assured he could.

Some individuals in the centres maintained they could talk with them both but I was never able to pass beyond asking questions requiring a yes/no response, which could be given by a nod of the head. Other physical activity was difficult for them both since they had little or no control over their limbs which invariably began to shake, sometimes violently, when they tried to concentrate or became excited. Consequently the use of two-dimensional communication devices, such as word boards, for example, was out of the question without help to steady their arms or legs. With reluctance I decided I would have to exclude them from the interviews. I explained to each individually my reasons for this decision and believe they both understood my predicament.

During the first six months of participant observation I discussed with both users and staff the idea of their being interviewed in a more formal setting. I had decided at the outset to conduct the interviews in (the second half of the period devoted to empirical research. Although they had already been told of my intention by Mrs B, I felt this policy could help to alleviate problems during the actual interview period in case some individuals were apprehensive. As it turned out another user, Amy, decided not to take part in the interviews. She did not give a reason and although I broached the subject on several occasions she would not change her mind. In all, therefore, there were thirty-three Contact user interviews. 3

It is important to remember that users' families also benefit from day centres. But while I have had several informal conversations with parents and siblings of some members, I only interviewed one individual's mother for this study, Mrs H. This is not because their impressions of the service are unimportant, but is solely due to the temporal constraints of the study. -I endorse Caner's (1981) contention that further research in this area is sorely needed. As the following chapter shows, Mrs H's inclusion is necessary because she was partially, if not wholly, responsible for Contact's formation.

Choice of staff interviewees was less straightforward than for users. Clearly the accounts of all those permanently assigned to work within the Contact format took precedence. But because the group utilized the buildings and resources of three day centres and because users and staff were not rigidly confined to one particular area in two of those centres, those staff peripherally as well as those directly involved with Contact had to be included if anything like an accurate picture of the current provision was to be achieved. However, apart from the practical problems, it did not seem appropriate nor necessary to include all the workers from each centre, since it was clear that several had little contact with the younger users. This was particularly pertinent to the Engineers' day centre where the Contact group was consigned to one specific area of the building. Here they hardly



ever interacted with others, users or staff, apart from the Officer in Charge (OIC) or Manageress, Mrs W, and an arts and crafts teacher named Hilary.

*Table 3 Staff Respondents*

Name	Functions	Unit	Other information
Jayne	SAO	Contact group	-
Jackie	AO/SAO	-	-
Patrick	AO	-	-
Annie	CA (GS)	-	-
Peter	CA (GS)	-	-
Mary	CA (GS)	-	-
Tracy A	CA (GS)	-	-
Tracy B	VW/CA (GS)	-	-
Sean	VW/CA (GS)	-	-
Barbara	VW	-	-
Andrew	OIC	Alf Morris Centre	
Bob	AO	-	-
Rick	AO	-	-
Anrea	CA	-	-
Maria	CA	-	-
David	Tutor	-	Drama
Prudence	Tutor	-	Music and Drama
Margaret	Tutor	-	Literacy/Numeracy
Sandra	OIC	Dortmund Sq'r Centre	-
Denise	AO	-	-
Vera	CA	-	-
Sally	CA	-	-
Jimmy	CA	-	-
Janis	VW	-	-
Jessica	CO	-	Ex Contact User
Mrs W	OIC	Engineers' Centre	
Hilary	Tutor	-	Arts and Crafts
All Units			
Gef	Transport Manager		
Jennifer	Specialist social worker for the younger physically impaired		
Mrs B	RDCO		

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OIC =	Officer in Charge	SAO =	Senior Activity Organiser
AO =	Activity Organiser	CA =	Care Assistant
(GS) =	Government Sponsored Work Scheme		
VW =	Voluntary Worker	CO =	Clerical Officer

RDCO = Residential and Day Care Officer

Since the younger impaired were situated at the Alf Morris centre for three days of the week and because the level of user / staff interaction was relatively high at this unit, the majority of general staff interviewed came from here. Given these general considerations regarding inclusion of staff it soon became clear that my original target of twenty-four staff interviews would prove insufficient. In the event I talked to thirty staff in the semi-formal interview situation. Table 3 shows each staff member's name, their designated functions within the system, the centres in which they were based and any other information which explains their inclusion.

### The Interview Schedules

During the first six months of participant observation the problem of interview schedules was never far from my mind. I did not wish to distort, constrain or 'impose violence' upon the statements of the contributors by the use of fixed-choice questions, but I was also aware of the advantages of this type of item, especially for people who demand 'hard evidence' to support an argument. It was my aim from the outset that this analysis should be accessible to everyone involved with the day centres, particularly policy-makers. It was important that the general meaning and phrasing of the questions used should be clear, concise and unambiguous in order that the respondents were not confused or put off by the language used. I support the view that meaning and meaning systems are best treated as sensitizing concepts which are

a means of exposition which yields a meaningful picture, abetted by apt illustrations which enable one to grasp the reference in terms of one's own experience (Blumer, 1954, p.9).

This is what I hoped to achieve for myself and for the reader. Consequently during the first two or three months in the centres I used the ample opportunities available to talk to people about their lives and their attitudes concerning current day centre provision. The ideas about what needed to be asked were gradually formed throughout this period.

It was ultimately concluded that a semi-standardized interview format would be the most appropriate for my purpose. This involves the interviewer asking specific questions, but being free to explore and probe as s/he sees fit (Hughes, 1981). The questions are essentially conversation openers and though many of the items may appear to require only a binary response, as the conversation progresses the respondent is given the opportunity to elaborate upon their position or change their mind if they feel so inclined.

This type of approach also allows the interviewer freedom to phrase and re-phrase questions as necessary. In theory this strategy favours

the creation of a situation which allows the respondent to define what is significant to her/him in the area of questioning, how much time should be devoted to particular issues and so on (Voysey, 1975, p.81).

This was the type of interaction I hoped to attain during the interviews. Such considerations are of particular importance when talking with people who through no fault of their own may have a limited vocabulary. By the time of interview, however, most respondents knew me sufficiently well not to let anything pass that they did not understand. On more than one occasion in both casual conversation and later in interview, I was told in no uncertain terms that 'You'll 'ave to say that again. .., in English this time Colin so's I'll know what you're on about'.

Three interview schedules were finally constructed, one for each group of potential contributors, that is, (a) users; (b) direct service staff including VWs, care assistants (CAs) and teachers; (c) senior staff such as senior activity organizers (SAOs), activity organisers (AOs) and managers (OICs). Much of the initial inspiration of the item construction came from the questionnaires used by Carol Edwards and Jan Carter for the National Day Centre Survey conducted during the 1970s (Edwards and Carter, 1980). Item schemes for the auxiliary staff were conducted as appropriate on an ad hoc basis. The schedules used for the RDCO followed a similar pattern to that used for the senior personnel but were amended with questions relating to the relevant data already received, from both observation and the preliminary interpretations of the other interviews. Mrs B was formally interviewed as the empirical research drew to a close.

In broad terms all the interview schedules followed a relatively uniform pattern covering four principal areas. The choice of this formula was determined by a combination of the general hypothesis outlined earlier, plain necessity and the naive hope that comparison, quantification and finally conflation would be greatly simplified. The areas of common ground included biographical information, organization of the day centres, specifics of user participation and control in the units, and finally social considerations relating to the external environment and the future. In many respects the first section speaks for itself. Respondents were asked about their background and specific items related to their "family, education, employment experience prior to entry into the day centres and how they first became involved. At this point users were asked to talk about

their impairments and the subsequent effects in terms of functional limitations. Throughout this study all references to user disablement are based solely upon users' interpretation of their abilities without recourse to official estimations unless otherwise stated.

The items relating to the centres began with questions concerning attitudes toward the service in general, staffing -levels, function and training, available facilities and activities, preferred activities and use of time spent in centres. The third section focused upon the mechanisms for redress of grievances within the system, internal organization, user involvement in policy making, attitudes toward user involvement, rules, sanctions and control. The final element of the interview schedule asked respondents to comment upon the day centres generally, the practice of mixing user groups, the possibility of heightened levels of integration with the able-bodied within the units, and how the service might be improved. Users were given the opportunity to give details of their recreational activities and social lives outside the centres, comment upon their subjective experience of societal attitudes and treatment of the impaired and their hopes and aspirations for the future. 4

#### Data Collection

Information gathering during participant observation was by means of note-taking and the use of a hand-held dictaphone. With reference to the former, would frequently disappear into the office or cloakroom as the necessity arose to "frantically scribble down important data concerning relevant spontaneous conversations, accidents etc.. If I was particularly interested in someone's conversation I would ask them if I could use their comments for my research. Fortunately no one ever refused. At meetings, discussion groups or important events I would simply sit, as unobtrusively as possible, taking notes as necessary. At the outset this practice naturally aroused interest from both users and staff who wanted to know what I was writing about, although few people actually read what I had written. Indeed, at first my note-taking became something of a joke among some of the users. But the novelty soon wore off and my behaviour was tolerated.

Initially I intended to use a tape recorder but this proved impractical because of the poor acoustics of the rooms in which activities took place. The dictaphone also proved less successful than I had hoped for similar reasons. Although it was easy to carry about, fitting neatly into a jacket pocket, the microphone was so sensitive that it tended to pickup every sound in the room, and there is frequently a great deal of sound in a day centre for young people. Consequently I had to find somewhere relatively

quiet before its use proved effective. At the end of each working day notes were rewritten and any taped comments written down. They were then filed under appropriate headings, for example, routines, activities, conflicts, etc., and a diary was kept documenting the sequence of the day's events as they unfolded.

Originally I had intended to hold the interviews in the respondents' homes as I believed that in their own environment they would be relaxed and more open in discussion. I decided against this approach for two reasons. Firstly, as my knowledge of the users grew it became apparent that a number of them were less likely to speak openly about their lives and their attitudes to the day centre service if there was any possibility of them being monitored by their parents. This suspicion was confirmed immediately before the period of interviewing began when I visited one individual's household. Because he was confined to a wheelchair, and due to the size of the house, his mobility was restricted almost exclusively to the living-room-cum-lounge. This meant he was in constant earshot of his mother. It proved impossible to hold a conversation without the mother's intervention. The second reason concerns transport. Since I do not drive, actually getting to and from the respondents' homes would have taken a great deal of time as many live outside the centre of the city in which the study took place.

Founded upon the belief that the views of the users should remain paramount, it seemed appropriate to interview this group of respondents first. But after six months in the centres it was inevitable that I would become aware of those who would have the most to say and those who would be shy. In order to circumvent any accusations of preferential treatment toward any specific individual, I decided that the simplest method of selection should be alphabetical order. This method was easily understood and was generally accepted. All interviews were prearranged at least one week in advance. In most instances the choice of date and time was left to the respondent.

When users were absent due to illness the next candidate on the list was asked if they would step in 'and get it over with'. They usually agreed. Apart from Amy, no one refused. All the user interviews were held upon day centre premises. For that with Mrs H, I went to her home. The longest user interview lasted one hour and fifty-five minutes and the shortest just over three-quarters of an hour, the mean being one hour and twenty minutes.

Apart from Jayne, the SAG for the Contact group, who left to undertake 'in-service' training half way through the study (January 1987) and was interviewed prior to her departure, all interviews of staff were conducted

after completion of those with the users. The order of selection was largely determined by grade, those at the bottom of the staff hierarchy first and management last. Primacy was accorded Contact workers, then staff from Alf Morris, then Dortmund Square, and finally Hilary and Mrs W from the Engineers' centre. Discussions with the auxiliary personnel were undertaken as the interview period drew to a close and the last semi-formal conversation held was between myself and the RDCO, Mrs B. The reasoning behind this strategy was that if points considered sensitive were raised in discussion with those in positions of power pressure might be brought to bear upon those lower down in the structure. In retrospect this was perhaps over-cautious, but at the planning stage it seemed a sensible precaution to take.

As with user interviews, the time and venue for the staff contributions were arranged in advance, normally a week to ten days, in order that the interviewing process would not clash with the general routines of the centres. Most of the interviews were conducted during working hours, although all the CAs assigned to the Contact group and those who worked at the Alf Morris centre were interviewed when their shift had finished. The sites for these discussions were the same as those used for the users, except for two, Janis, a VW, and Denise, an AO, both of whom were based at Dortmund Square. Janis only worked on Thursdays, when the young impaired were at this centre, and felt that our conversation would be less intrusive on time spent with the users if it was conducted on another day. Consequently the discussion was held in the back room of her shop one Wednesday morning. At the time of her interview, Denise had just begun an in-service training course. Our conversation took place in her home on one of her 'study' days. The duration of staff interviews varied between one hour and five minutes for one of the VWs, to just over two and three-quarter hours for the SAG for the Contact group. The mean for the thirty discussions was two hours.

On average the length of time spent in conversation with staff was longer than that with the users. This was not because the schedules for the former were any longer but simply reflects the fact that many of these respondents, particularly those at the higher levels of the day centre hierarchy, were more thoughtful and loquacious in their responses to the questions, often using examples to illustrate statements or re-emphasizing points which they felt were particularly important. There was no noticeable difference between the amount of time in conversation with some of the younger, less experienced staff than there was with the users. All the interviews were tape recorded. The quality of the recordings was enhanced by the fact that the interviews were held in quiet surroundings

with only myself and the respondent present. The tape recorder never let me down. The only difficulty experienced was due to my reluctance to spend money on new batteries resulting in the playback quality of one conversation being particularly faint.

Although some of the users had problems with their speech this was not really a cause for concern. By the time the interviews came round I had become sensitized to likely difficulties of some individuals and felt confident enough to mention if I had trouble understanding what they were saying. In addition, I had few of the problems of self-presentation which plague many researchers. When the interviews began everyone knew exactly who I was and why I was there.

At the start of each interview I told the respondent that any information received during the subsequent discussion would be treated in the strictest confidence and gave a pledge that any quotes used in the finished product would preserve her/his anonymity. At the end, subjects were asked to refrain from discussing our conversation with others in the centres in the interests of validity. I believe the majority respected this request. All the respondents were asked if they would like to hear the playback of the recorded interview, but only two of the users wished to do so. Both lost interest after the first ten minutes or so. Everyone was given the opportunity to view the written interview transcript once complete. One CA, Annie, who was leaving the service, requested to do so but after reading it carefully she returned it without comment.

Each interview was transcribed in full in longhand, catalogued according to the date and indexed by page and line where it was felt statements were of particular importance. This technique proved extremely time-consuming and resulted in a mountain of material which defies quantification. This method may seem a trifle ponderous and indeed unnecessary but may be explained in the context of researcher insecurity. The interview transcripts were subsequently read, and re-read and coded in relation to specific areas of interest and the sequence of events that occurred throughout the year. Quantification and comparison were then completed and a preliminary synopsis of both user and staff interviews, of approximately 30,000 words, was produced to synthesize the salient tenets of the central argument into a more manageable form.

Where respondents' comments are used in the text every effort has been made to reproduce the exact colour and texture of the language used as faithfully as possible, with reference to dialect etc. The abbreviations used to depict it in print, when appropriate, are analogous to those used by



Geoffrey Pearson who recently conducted an ethnographic study of heroin misuse in the same part of the country (Pearson, 1987). Each respondent was told of this intention and only one user offered any reservations. His concern was not about how the statements were reproduced but rather what was reproduced. He told me,

'I don't care 'ow you put it ....., as long as you don't med' us sound thick. '\* -Billy

As they appear in the analysis statements made during interview are marked \* and those made in conversation during participant observation +.5

I endorse the point made by Max Bloor (1983) that contributors should be given the opportunity to pass comment on the investigator's findings. With this in mind, the preliminary conclusions of the study have been discussed at length with several of the respondents. Moreover, one year after the empirical research had concluded I returned to the centres on a number of occasions to assess any changes which had occurred during this period and discuss those changes with those who took part. A brief commentary on those visits appears in Chapter Eight.

#### Difficulties Encountered during Data Collection

Apart from Michael and Alison, one other user in the Contact group, a young man named Charles who was severely paralysed in a motorcycle accident, had no means of verbal communication. As he could only control, with any accuracy, the little finger on his right hand, communication with him was only possible through the use of a small hand-held card containing the letters of the alphabet. In response to conversation he would spell out his reply using his little finger. The card was held by the person communicating with him. If he wished to 'say' something he would attract attention by smiling and nodding his head. Conversation by this method was not really a problem although a little slow. My discussion with Charles was one of the longest of the user interviews.

A principal worry with regard to the user interviews concerned discussion of the knowledge individuals had of their respective impairments, and their aetiology. In cases where it is known that impairments are caused by a progressively degenerative disease which may result in a relatively short life span and when the condition is at a visibly advanced stage, this is an area of considerable delicacy. This was the situation with one of the respondents, Gavin, who had muscular dystrophy (a genetically transmitted

degenerative illness causing progressively severe impairments and premature death, often at a relatively early age). Before his interview I was extremely apprehensive about posing items relating to Gavin's knowledge of his impairments or his illness, as I had never heard him discuss these subjects in general conversation. After careful consultation with the senior staff, who were in regular contact with his mother, it became clear that no one in the units had any real idea of how much he actually did know, or indeed wanted to know about his condition. I have to admit that during the interview I deliberately avoided raising these issues, other than to ask if he knew the name of the disease, which he did. Gavin died three months after the empirical analysis was completed. He was nineteen.

A similar problem occurred with another user, Billy, who suffered from Friedrich's ataxia (a progressive inherited disease of the central nervous system affecting the spinal column, coordination and occasionally the eyes). During the interview Billy refused to discuss his condition and was evidently agitated by its mention, saying that he did not like to talk about it with anyone. I quickly changed the subject, but it became apparent later that this behaviour was largely attributable to ignorance. Some days after the interview he explained apologetically that he had only recently been told of the seriousness of the illness, by which he meant being made aware that a cure was unlikely. He only knew how the disease had affected him to date, which was visible to all, but little else.

Difficulties encountered in staff interviews were relatively minor. One girl, Andrea, developed a 'headache' immediately before the scheduled discussion. But a date was fixed for the following day and the ensuing conversation progressed without a hitch. One of the OICs postponed our meeting three times, due, she said, to the pressure of work. Because I was aware that her unit had in fact the highest level of staff and the lowest user attendance figures this explanation seemed somewhat hollow. I approached her re-emphasizing that her compliance in the investigation was voluntary. She apologized and reassured me she wished to take part. A fourth date was fixed for the interview. At this meeting she maintained that she could only spare me half an hour. In all her contribution took three separate interview sessions to complete.

During two of the other staff interviews, Mrs W, the OIC at the Engineers' day centre, and Jackie, the AO for the Contact group, the conversation was interrupted a number of times, six for the former and four for the latter. The discussion with Mrs W was held in her office and our conversation was punctuated by the telephone and by staff using the telephone or making enquiries about activities or other matters pertinent to the days' events. A

similar situation arose in my discussion with Jackie, although instead of staff seeking her attention it was the users. After the fourth interruption it was mutually agreed that in order to avoid further hindrance the interview should be abandoned until the users had gone home later that day. This we did and our conversation proceeded without incident.

## Conclusion

From the above discussion it may appear that the completion of this study was relatively trouble-free. This was not due to any particular skill on my part, but rather a number of factors which included constant support and much needed advice from both my supervisors, the perceived importance, by all those taking part, of the subject under investigation, the willingness of all the individuals who used and worked in the day centres to contribute to the study, and the choice of methods used, which were undoubtedly ideally suited for this purpose. By drawing upon the information provided by these individuals and the employment of these methodologies, the following chapters will develop fully the argument outlined in Chapter One.

## Notes

- 1 It later transpired that the policy of non-involvement by staff in the affairs of the Insight groups was a deliberate strategy by management intended to stimulate higher levels of user autonomy and self-determination within the centres.
- 2 To ensure confidentiality all names used in this study have been changed.
- 3 A detailed discussion of the social characteristics of the user sample appears in Chapter Five.
- 4 Copies of the three principal interview schedules used in the study are provided in the Appendix.
- 5 Dates when the interviews were conducted are given in the Appendix.