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INTERACTIONS AND RELATIONSHIPS IN ADULTS WITH INTELLECTUAL DISABILITY

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ABSTRACT

This research concerned the social experience of two groups of adults with intellectual disability (mental handicap), those with verbal skills who could describe their experience and those with profound disabilities whose needs were interpreted by carers. Conceptual issues have been discussed to provide a framework for understanding their relationships and also for understanding intellectual disability itself. Social constructionism has influenced the investigations.

Previous research shows that disabled people experience relatively little social contact regardless of their level of ability. Interactions and relationships were investigated so that practitioners aiming to improve intellectually disabled adults' social experience may have relevant information. It has been assumed that more interaction is better as it allows people to reflect upon themselves with regard to others, to construct themselves through their interactions.

These investigations fall into two main sections, the first a discussion of attitudes toward self and others held by people who had, or did not have, a peer-group friend. Results suggested that further examination of the role of the self-concept in friendship formation would be fruitful and that people without a peer-group friend were similar to lonely non-disabled adults.

The second section examines profound disability and contains a linked series of studies of adults' interactions with keyworkers. Results suggested that two interaction strategies used by staff were associated with increased positive responding from clients; that the developmental age of clients did not distinguish between them in their social responses to staff; that there was little evidence of turn-taking or the importance of staff making responses which follow the client's lead. Results were discussed in terms of their contribution to an alternative model for understanding profound disability.

The project as a whole was discussed in terms of the interaction between method and conceptualisation and concludes with a number of recommendations for practitioners.

PART I

CHAPTER 1. INTRODUCTION

People with intellectual disabilities experience relatively little social contact and relatively few social relationships. This generalisation holds for children, for adolescents and for adults; it holds for people with mild and moderate disabilities as much as for those with severe and profound disability; it holds both for people in segregated settings and for people in integrated settings.

Social constructionism is discussed in the second section of this chapter. This theory is being re-examined by many psychologists. It assumes that knowledge of oneself and the world is obtained through social negotiation, giving a central position to social interaction rather than seeing it as one of many aspects of human experience. If this theory is accepted then the limited social lives of people with intellectual disability have far-reaching consequences.

Recent trends in psychological research are discussed in the last section of the introduction as these influenced the design of the investigations into interactions and relationships which are reported subsequently.

1.1 RESEARCH CONCERNING THE SOCIAL LIVES OF ADULTS WITH INTELLECTUAL DISABILITIES.

The studies reviewed in this section examine evidence for the view that many people with intellectual disabilities have difficulty in making and maintaining supportive social relationships. Research is discussed according to the type of social contact available in different situations. The first social setting is that of adults living or working independently; the second concerns adolescents and young adults, many in educational settings; the third setting is that of adults living in staffed residential services; the fourth setting is the segregated school and the final setting is within the family.

Some of the topics introduced here are developed further in chapter 2, which describes research relevant to understanding the social experience of adults with mild and moderate intellectual disability and chapter 4, which details studies relevant to the social needs of adults with profound intellectual disability.

Zetlin & Turner(1984) described a study with 46 intellectually disabled adults living independently. The authors related the individuals' social contacts to their self-image and their parents' view of disability. They used participant observation to collect the data. They separated the 46 people into four groups: those who accepted their disability, those who accepted they had difficulties in some areas but saw themselves as non-disabled, those whose views on disability vacillated and those who denied both being disabled and having any difficulties. The overall quality of life reported by individuals in the first,second and last group was happy while the quality of life of the third (vacillator) group was reported by them to be miserable. The 'acceptors' preferred to make relationships among non-disabled people; the 'qualifiers' preferred to be friends with other mildly disabled adults; the 'vacillators' preferred to make relationships among mildly disabled or non-disabled people while avoiding contact with severely disabled people; finally, the 'deniers' preferred family relationships. The researchers noted that the 'vacillators' seemed to have shallow, unstable relationships and a miserable quality of life.

Kaufman (1984) described a study carried out in parallel to Zetlin & Turner's work above, apparently with the same subjects.

Kaufman felt that those who had lived independently the longest (over 9 years) were the most socially satisfied. This study again used participant observer techniques and gave no information about how the sample was derived. There was some discussion of whether friendships were reciprocated or not but the criterion of 'mutuality' used to describe a reciprocated friendship appears to have been applied rather loosely. Kaufman illustrated the concept of mutuality by one example, that of a disabled man mixing with non-disabled people at a train-spotting club. No single individual from the club is identified as having a mutual relationship with the disabled man. The issue of defining and identifying a mutual relationship or friendship is discussed further in chapter 2. No indication was given of the number of reciprocated friendships (as defined by Kaufman) in the sample except through the comment that non-reciprocated ones were more common. This study was reported in a rather subjective manner which leads one to query whether the views expressed were those of the author or the participants.

Atkinson & Ward (1987) described 50 people living alone or with friends 5 of whom had made relationships with their neighbours. These were described as reciprocated relationships without full discussion of the term. Most of the discussion of these people's social lives was descriptive, the authors observing that placing people in ordinary houses was insufficient for them to make relationships with others in the community. Dudley (1983) studied the friendships of 27 people living independently. Between them these individuals described 115 friends: 85 were people with intellectual disabilities, 21 were staff or family and 9 were non-disabled people unconnected with the service. On following up the nine relationships with non-disabled people Dudley found that nearly all were fantasy friendships with people the nominators had met once or twice; one of them was a reciprocated relationship.

Flynn(1989) surveyed all of the people living without residential staff in six districts of North-west England. She found that the longer the people had lived independently the less satisfactory were their lives in terms of number of visitors, experience of loneliness and number of positive relations with people. 62 of the 88 people interviewed were receiving counselling on interpersonal matters from their social worker, the latter's most frequently cited activity.

Flynn's analysis of study group members' social support suggested that social services staff played a more central role in their lives than did family or friends. Problems with money and social isolation were two dominant themes affecting people equally whether they lived alone, with a partner or friends. She noted that many people described their visiting social worker as a close friend while the social workers planned to withdraw as their clients became more independent. Incompatibility between these two views often left the disabled people feeling hurt and bewildered when the social worker's visits tapered off.

Schalock & Lilley (1986) also found that most people in community living projects in the USA were lonely and socially isolated, with project staff providing the main source of social contact.
In similar vein, Halpern, Close & Nelson's(1986) survey of people living semi-independently found that they cited two problems most frequently: coping with money was the first and coping with personal relationships was the second. Gollay et al (1978) had found that difficulties in social interaction and loneliness were a significant problem for 40% of the 440 deinstitutionalised people whom they interviewed. Despite a decade of radical service change and the growth of community support this problem remains unaffected.

An investigation of the social interactions between intellectually disabled and non-disabled people working together reiterated Atkinson & Ward's (1987) observation that placing people into situations does not necessarily lead to the development of relationships. Chadsey-Rusch et al (1989) found that contact between disabled and non-disabled coworkers tended to be limited to work-related matters: contact at break, lunch or out of working hours occurred signficantly less frequently than it did between non-disabled people. Nevertheless, this study did find that a quarter of the disabled people had visited their coworker's home, suggesting that worker pairing can be effective.

The following two studies investigated the relationships made by young people with all types of intellectual disabilities. Kuh et al (1986) carried out an evaluation of the unmet needs of young disabled people aged 16 to 25 years. 35% of the intellectually disabled group expressed loneliness (or were described as such by their carer) compared with 12% of the non-disabled control group. Overall Kuh et al identified 59% of the intellectually disabled group as having unmet social needs compared with 31% controls. For the intellectually disabled group this was the third most frequently identified need - only needs for accommodation (84%) and occupation (64%) were more pressing.

Gilkey & Zetlin (1987) studied the social relationships of young intellectually disabled adults in an American high school. The researchers found that the young disabled group's overall pattern of social interaction was low. Their contact with non-disabled students was minimal and they had no close relationship with other special education students either during classes or outside them. At interview the disabled students nominated teachers, aides, gardeners and other adults as their friends. Some nominated their parents, none nominated a classroom peer.

It appears that neither young adults nor adults living independently make many relationships with non-disabled people. Whether they make relationships with other disabled people is less clear. It appears that young adults do so rarely and that adults living independently do so at times; however, the latter group may not value them highly and the relationships generally seem to be insufficient to meet the social support needs of the majority.

Turning to the social lives of people living in staffed residences introduces two extra dimensions. The first is the nature of their relationships with staff members and the second is the effect of such environments on the relationships between disabled people. Most of the research on staff-resident relationships has been carried out in NHS settings in Britain. In America investigations of the social relationships between residents and between staff and residents have been carried out in community homes: these seem to be similar to hostels run by social services or the voluntary sector in Britain.

Within hospitals the importance of contact with staff was emphasised by Klaber (1969) who found that a composite score of institutional effectiveness was correlated with the amount of contact nursing assistants gave to disabled children.

Three themes can be traced through the literature on staff-client interactions: the duration of interactions; the distribution of staff time between people; and the types of responses staff make to different client behaviours.

Kandler et al (1952) noted that the duration of staff-patient interactions in a psychiatric hospital was generally shorter than one minute. Moores & Grant(1976) investigated this along with a number of other variables in a study comparing the effects of high and low staff ratios in hospitals for adults with intellectual disability. They found that 78% of all observed interactions in the first hospital lasted for less than 30 seconds while 87% of interactions lasted for less than 30 seconds in the second hospital. It was the second which had a significantly higher staff-patient ratio.

With regard to the characteristics of residents receiving most staff interaction Grant & Moores (1977) found that their results were similar across the same two settings despite the difference in staffing level. In the two hospitals 20% of residents received 37% and 43% of staff interactions respectively. Associations between resident characteristics and interaction frequency were all insignificant except for social maladaptation score from the Adaptive Behaviour Scale. Examining interaction types, however, showed that residents who displayed more adaptive behaviour and had higher independence scores were more likely to receive interactions from staff which were verbal and positive in nature. Staff were more likely to use nonverbal interactions towards residents with socially maladaptive behaviour. Grant and Moores felt that the residents in greatest need of warm and 'developmentally promoting' contacts were the people least likely to receive them. They found few differences in interactions between staff and residents across settings within hospitals, noting the same pattern of interaction in wards, in industrial therapy units and in occupational therapy units. They noted that all of their observations had been taken at times of maximal staffing. They suggested that future staff training should emphasise both the contingent use of reinforcement and the importance of interacting with the residents.

A number of studies of the types of responses made by staff to various resident behaviours were carried out in the 1970s. Klaber's (1969) study has already been mentioned. The series of studies made by Raynes et al(1979) produced many results, one of which was the importance of staff using informative speech to residents.

In behavioural research Warren & Mondy (1971)examined the types of responses made by staff to particular behaviours of severely and profoundly disabled adults; this was replicated by Felce et al(1987). Felce et al (1987) compared staff-client ratios, client behaviour and staff responses in large institutions, large community homes and two small group homes. In the institutions and large community homes the frequency with which staff made encouraging responses ranged from 3.6% to 0.8% of intervals observed, while the frequency with which they made neutral responses ranged from 6.4% to 1.9%.

Felce et al (1987) found that the pattern of interaction was significantly different in the two small community homes when compared with that found in hospitals and large community homes. Staff in small group homes made encouraging responses in 14% and 25% of intervals and neutral responses in 11% and 14% of intervals. This difference could not be explained by a higher staff-client ratio alone. They suggested that training in behaviour management methods provided for community staff may have been a factor. The study was primarily concerned with social reinforcement of appropriate behaviours in the clients and so it did not examine the quality nor the duration of the interaction between the people. The authors concluded: "We found that many of the problems of staff interaction reported in the earlier study are still current"(p502).

Bercovici (1983) introduced a more ecological approach to studying staff-resident interactions in community homes. She felt that the behaviour of residents and staff was a function of the social organization of the institution and that their behavioural repertoire was one which coped with the current environment. Social distance between staff and residents was observed both in their interactions and in patterns of behaviour such as eating. Bercovici felt that there was a process of depersonalization operating on the residents coupled with a lack of opportunity for decision-making. She recommended that these and other aspects of the environment should be tackled before residents' relationships with staff or with one another were considered.

The relationships between residents in American community homes was investigated in a series of studies designed by Berkson & Romer (1980). These are discussed in detail in chapter 2, along with Landesman-Dwyer & Berkson's (1984) research into the social interaction between people in different residential services.

If staff were in frequent social contact with intellectually disabled people this would not necessarily meet the disabled people's long-term social support needs. A recent British study (Allen et al 1988) found that the average turnover rate for hospital staff was 18% per year while the average for community staff was 23%. On the basis of these figures it seems unlikely that a network of stable relationships can be developed if staff are the main human resource.

Two studies in schools for children with severe and profound disabilities report results similar to those on staff-adult interactions. Brusca et al (1989) carried out an observational study of the effects of staff contact and activity on the stereotyped behaviours of 3 severely and multiply disabled children in a residential school. The staff observed on this occasion were teachers and teaching assistants. Overall they found that teacher-pupil interactions concerning a task occurred in 24% of observation intervals, interactions without a task or goal occurred in 4% of observation intervals and no contact occurred in 72% of observation intervals. Their major finding was that there was a decrease in stereotypy when the children received naturally occurring interactions related to tasks. However, the result of interest here is the low rate of staff interactions with residents which the authors felt could not be explained by teacher-pupil ratios as these were typically 1:2.5. They did not report frequencies or durations of social contact.

The second school study was carried out by Ware & Evans (1986). This was an observational study of the interactions between nine children in a special care class with a staff:pupil ratio of 1:3.They looked at whether staff initiations allowed for a response from the child and also whether staff responded to initiations from the children. Any behaviour from the child was presumed to be an initiation. They found that the nine children's results tended to group according to developmental age. The most profoundly disabled were as likely to ignore adult initiations as to respond while the less disabled group were more likely to respond positively. The most disabled children were more likely to be approached by staff in a manner which does not allow for a response when compared with the rest of the group. Examination of the responsiveness of staff to initiations from all of the children showed no difference between the two groups: about 73% of all initiations from the children were ignored.

These school studies seem to underline the difficulty which staff experience in interacting positively and responsively with profoundly disabled children even when the environment is pleasant and the staff:pupil ratio good.

The final avenue for social contact is people's family networks. Grant(1989) studied a population over a two year period. During that time there was considerable contraction of people's social networks. This was almost wholly because of change in family relationships while nearly all sources of expansion were professional contacts. As family members die or move and are not renewed by fresh relationships the pressure on remaining network members (80% of which are mothers) grows. A number of complex interdependencies between the person with developmental disability and family members were observed. These were described as 'embedded' family relationships which further isolated them from their community.

SUMMARY OF SECTION 1.1

Flynn (1989) found that adults living independently place importance on their social contact with staff and that the longer they had lived independently the more lonely they were. This contradicts Kaufman's (1984) result but some doubts were expressed about her method. A number of other studies support the finding that most disabled people living in community projects are socially isolated. The frequency with which staff were nominated as friends by intellectually disabled people was also mentioned by Dudley (1983) and by Gilkey & Zetlin (1987). There was little evidence of a growth of relationships between disabled and non-disabled people from either residential or work-based projects.

Young adults were found to have more needs related to their social lives than non-disabled controls and were found to have very low levels of social interaction when observed in a high school.

Adults living in staffed residential settings were found in general to have short, infrequent interactions with staff. This pattern of interaction was found to be common to a well-staffed and a poorly staffed hospital and also to be found on wards, in industrial therapy units and in occupatiuonal therapy units. Staff in hospital and large community homes were found to provide fairly low rates of encouragement for appropriate behaviours or inappropriate ones and it seemed to have changed little in 15 years. However, there was significantly more encouragement for appropriate behaviours provided by staff to severely and profoundly disabled residents of small group homes. Two studies of staff-pupil interactions in schools for severely and profoundly disabled children found low interaction rates and limited responsiveness of staff to pupil initiations. This research was put into a life-span context by being reviewed alongside data on staff turnover rates.

Research into relationships between adults with intellectual disability in large community homes was alluded to but will be discussed further in chapter 2.

The final source of social contact discussed was that of contact with families. Zetlin & Turner (1984) had found that about one quarter of their group valued family relationships most highly and had no interest in developing relationships with other people: however, a network analysis showed increasing pressure on mothers to meet all of the person's social needs with less and less assistance as they grew older.

It appears from this evidence that the area of social relationships is one of particular difficulty for people with intellectual disability and one which is unaffected by changes in service provision.

1.2 SOME CURRENT ISSUES IN PSYCHOLOGICAL RESEARCH RELEVANT TO PROJECT DESIGN.

Three major themes affecting psychological investigation underpin this research. The first is a shift in philosophical assumptions; the second concerns the importance of socio-political issues and the third is the growth of qualitative methods of enquiry. These are discussed below.

1.2.1. Philosophical assumptions.

Harre (1981) has argued that all branches of science move cyclically through positivist phases. He described the 'retreat into positivism' as being due to loss of confidence in the prevailing schema, where too many competing explanations of phenomena abound. However effective the behaviourist approach has been in making a contribution to the lives of people with developmental disabilities there is little sign of it developing as a coherent body of knowledge. Harre's article describes an alternative philosophy of psychology based on realism.

It is a relatively simple matter to identify the paradigm shift away from behaviourism, less easy to agree on a new conceptual basis. Harre (1986) argued for a social constructionist approach. This idea was originally expressed by G.H.Mead(1934); it has recently been re-worked and developed by Gergen (1985), who explained the idea as follows. "Social constructionist inquiry is principally concerned with explicating the process by which people come to describe, explain, or otherwise account for the world (including themselves) in which they live" (p 266). Social constructionism has recently been applied to the psychological study of people with intellectual disability by Jahoda et al (1988), St Claire (1989) and Gallimore et al (1989).

Social constructionism has been criticised for its focus on cognitive aspects of interaction (Richardson, 1988) but the framework proposed by Lock et al (1989) could be seen to be equally relevant to affective and cognitive aspects of development. Richardson (1988) criticised social constructionism as being a nebulous approach which provides sketches rather than theories. The relevance of social constructionism to studies of interactions between people is discussed further in Chapter 4, in which the views of social scientists are considered alongside those of philosophers such as Buber (1967).

Some social constructionist themes were present in Kelly's (1955) theory of personal constructs when he placed great emphasis on the way that individuals construct their world by processes such as predicting the behaviour of others. Kelly's use of repertory grids for helping people to understand themselves in relation to important people around them is very much in tune with social constructionist ideas. Kelly saw his theory as a construction at that time which seemed to encompass the available evidence but which would be overturned in the light of new ideas in the future. He was not hoping to provide 'nuggets' of truth about humanity. Social constructionists' demonstration that socially negotiated concepts are developed between members of research teams even in traditionally 'hard 'sciences is again in tune with Kelly's view.

The ecological approach of Bronfenbrenner (1977) also places people within their social contexts. Tajfel (1984) noted the increasing importance of social factors in the study of social psychology, observing that the study of attitudes and opinions had given way to the study of social representations of social reality.

These theories are complementary, similar aspects with slightly different perspectives. Bronfenbrenner (1977) discussed the ecology more than the person within the context while Kelly (1955) did the reverse. It is possible that social constructionists can combine these into a whole which is manageable and useful. Valsiner's (1987) book synthesises some of these ideas.

Valsiner takes a social-contextual view of psychology, arguing that various psychological ideas are accepted by different countries at different times according to their existing cultural assumptions. This is seen as a process of assimilation and accommodation operating at a cultural level. He stated: "The main goal of this book is to analyze the epistemological state of affairs of the 'young' science of psychology....In their frequent quest for more 'empirical data' psychologists have taken the easy way out of the complex conceptual issues that the discipline has struggled with from its inception."p2.

Valsiner (1987) described four frames of reference for psychological research. The first was the intra-individual, a common focus of study within the person. The second was inter-individual, also commonly investigated. The third, individual-ecological examines the interplay between people and their environments while the fourth, individual-socioecological, looks at the way competent others facilitate interaction between an individual and their context. Vygotsky's work was given as an example of the latter. Valsiner noted that little psychological work was carried out within the last two frames of reference although these were of greatest interest to him. Selection of frame of reference was seen as an important element in decision-making about research design. Valsiner also proposed the following maxims about psychological research.

a) The study of developing processes may be more interesting than the study of static entities. From this perspective Piaget's theory of equilibration is seen as contributing more than his observations concerning the stages of development themselves. What should be of greatest interest to psychologists is the process by which people move between stages.

b) Research should be relativistic, by which Valsiner meant research containing cultural axioms and core theoretical concepts based on them. These should include reference to which of the above frames of reference the psychologist is employing. Experimental variables and data derived from them should be seen as active construction efforts by the experimenter. He argued that only by recognising these points would psychologists understand why there are many different perspectives based on empirical data, and so abandon attempts to reduce that variability to a single "true" perspective.

Valsiner amplified the relativistic approach as follows. "My aim is to treat the theoretical system and the psychological phenomena as interdependent and mutually important....a theory cannot be built without having reality as a basis. Likewise, no empirical study without a clear explication of its theoretical bases can result in new knowledge." (p13).

c) The person-environment separation is a false dichotomy since both constituents are interdependent. This follows logically from taking an open-systems view of the world.

d) Psychologists should cease to regard inter-indivual variability as a source of error which should be designed out of projects. He states that "Variability is not a source of 'error' in the case of complex phenomena in psychology, but an indicator of psychological processes that can generate a variety of psychological outcomes."(p23).

e) Research should concern the structural whole rather than assume that additive elementarism can capture complex developing processes. This point was made by Kelly (1955) in his discussion of research methods in psychology. Both men were criticising the separation of an event or process from its system, precluding the detection of relationships between phenomena.

Valsiner's book was not available at the outset of this research and so it did not influence the design of early sections. It offers a yardstick for considering the results, however.

1.2.2. THE IMPORTANCE OF SOCIO-POLITICAL ISSUES

In 1981 Reason and Rowan's edited book Human inquiry : a sourcebook of new paradigm research crystallised many objections about the way human "subjects" had been treated by social scientists. It contained papers suggesting that the research process was a legitimate topic for enquiry, that the apparent objectivity of the experimenter towards the subject was not a useful way to approach understanding people and that experimental designs involving deception were unacceptable. The importance of taking account of the "subject's" perspective was emphasised. It was suggested that a more appropriate model for research was one of negotiation between researcher and participants. This negotiation model had been used by researchers previously (eg Wood, McMahon & Cranstoun 1980) but it was elaborated by contributors to this volume. People were urged to be mindful of the social implications of research results for the client group involved and also to consider the political implications of the design.

Wolfensberger's (1972; 1983; 1985) publications on people with intellectual disability have also brought the political implications of service and research to the fore. He has drawn attention to service aspects such as treating adults as if they were children and the devaluation of the disabled person's perspective.

Generating conceptual frameworks for psychological investigation of, and intervention with, intellectually disabled people has been discussed by Cunningham & Davis (1985), Conti-Ramsden(1989) Landesman-Ramey et al (1989). The necessity for fundamental conceptual debate in intellectual disability was described by Baumeister (1987). He questioned the dominance of IQ, noting that intellectually disabled people grouped by IQ show greater within-and between-subjects variation than matched non-disabled controls and that that variation is one of the key characteristics of disability. Valsiner's (1987) point that psychological research in general should value individual variation is nowhere more apt.

Baumeister (1987) argued that the debate over whether intellectually disabled people are developmentally backward or different from others remains a fundamental issue (this is discussed further in Chapter 4). He also distinguished between structural features and control processes or, to use his computer analogy, between hardware and software in intellectually disabled people's information-processing systems. He suggested that structural features (invariant aspects of intellectual function) may define a "reaction-range" within which control processes (aspects of intellectual function open to training) can operate.

1.2.3 THE GROWTH OF QUALITATIVE METHODS IN PSYCHOLOGY.

Social anthropologists such as Edgerton (1967) used qualitative methods to investigate the experience of people with intellectual disabilities over 20 years ago. The development of appropriate qualitative methods in psychology has been slow. Reason & Rowan (1981) described one of the aspects of their new paradigm research as being objectively subjective. Some authors (eg Moustakas, 1981) have felt that the experimental method contributes to the model of additive elementarism more than it does to the structurally holistic approach.

Others have observed that the methodological rigour obtained by laboratory experiments can sacrifice validity. For example, Dunn (1984) reported that observations of young children in their own homes showed clear evidence that children as young as 14 months could understand events from the point of view of their sibling. Dunn reported some experimental psychologists' results suggesting that children under 5 years were unable to take another's perspective; they had been using relatively abstract tasks in formal laboratory settings.

Marshall & Rossman (1989) provide a useful guide to designing and carrying out qualitative research. They regard the method as suitable for research in some areas, for example when investigating a relatively new topic or when considering complex social systems. They also suggest that qualitative methods can give a different perspective to a topic, providing information which is complementary to other approaches. The essentials of this method are that data is collected in natural settings, that the perspective of the participants is central, that the design should be open-ended and that strategies for data collection are made explicit.

1.3 THESIS STRUCTURE

This thesis examines the social experience of two different groups of adults: people who are mildly or moderately intellectually disabled and people who are profoundly intellectually disabled. People in these two groups are often investigated separately because their different abilities require different methods of enquiry. Nevertheless, they are both members of a social group defined as intellectually disabled. It is likely that they both have social needs although the socio-emotional life of people with profound disabilities is not often considered (eg Hogg & Sebba, 1986; Ouvry, 1987).

The presence of some language abilities in the mildly/moderately disabled group permits a method which is discursive and places the individual's perspective in the forefront. The absence of speech in the second group leads to a different method of investigation which involves interpretation of the individual's experience. The thesis is therefore separated into four parts the first of which is this overall introduction. Part II considers literature relevant to the social lives of adults with mild/moderate intellectual disability followed by a report of data collection with people from this group (Chapters 2 and 3). Part III comprises an examination of literature relevant to the needs of people who are profoundly disabled (Chapter 4), combined with reports of a pilot study and three linked investigations into interactions with this group (Chapters 5,6,7,8, and 9). Part IV comprises Chapter 10 in which the research as a whole is discussed, future directions for research are proposed and conclusions are drawn.

PART II.

CHAPTER 2: A REVIEW OF LITERATURE RELEVANT TO RELATIONSHIPS BETWEEN PEOPLE WITH MILD OR MODERATE INTELLECTUAL DISABILITY.

Studies of the social contact of intellectually disabled people living in a variety of situations were reviewed in the previous chapter. They show that most disabled people have few relationships with other disabled people, very few with non-disabled people and that they have particular difficulty in making satisfactory social relationships. This chapter focuses on the relationships which disabled people make among themselves. Such relationships are important to community living projects as it is rarely possible for people to live alone.

Research on friendship, on relationships across the lifespan and on loneliness in non-disabled people is summarised in the first section followed by discussion of relevant psychological theories. The second section reviews psychological studies of relationships between adults with intellectual disabilities.

2.1: RELATIONSHIPS IN NON-DISABLED PEOPLE

Wright (1984) defined friendship as "A relationship involving voluntary or unconstrained interaction in which the participants respond to one another personally, that is, as unique individuals rather than mere role occupants." (p119). He emphasised that there were two separate components, voluntary interdependence and responding person to person, and that the more these were in evidence the stronger would be the relationship. Palisi & Ransford's (1987) discussion of friendship as a voluntary, mutual relationship between people who are not related to one another is similar. Adams (1989) described some conceptual and methodological issues of studying friendship. She suggested that the advantage of the experimenter using a particular definition of friendship was that it was clear that like was being compared with like while the disadvantage was that it may result in a limited study where unusual friendships are excluded.

Close personal relationships have been associated with the subjective well-being of non-disabled people (Deiner, 1984, reviews this). The changing role of relationships through the lifespan was reviewed by Dickens & Perlman (1981), who suggested that friendships peak in early adulthood and that the frequency of social interaction is high then. In childhood it seems that cognitive development determines relationships while demographic and sociological factors influence relationships in adulthood and old age. The theories of social development proposed by Bigelow & LaGaipa (1980) and Youniss (1980) emphasise the importance of the preadolescent period, from about 9 to 11 years, in creating the shift from dependence on parents and teachers towards peer support. Adams (1989) questioned whether there was an inevitable decline in number of friends and amount of social activity in old age or whether there was a cohort effect operating; if people maintain their pattern of social activity throughout life then the current group of socially active young people may behave differently as they age.

Allan's (1989) sociological analysis of friendship examines the constraints on people's friendship choices exerted by their social situation. This approach looks at what opportunities exist for the person to form relationships and Allan emphasises the importance of studying people within their actual social environment rather than within some artificial locality or neighbourhood. Allan's description of an immediate social environment is a space bounded by the demands and restrictions placed on the individual by their position in the social structure and their roles. This space represents the opportunities available to people to develop aspects of their personal life.

Factors affecting the personal space of non-disabled people are class (although younger people are no longer following traditional social patterns), domestic commitments, transport, gender, and the influence of the workplace, if any. The questions asked of all of these factors are what opportunities do they offer for making relationships and how much time, money and energy is left from these commitments to allow the person to maintain relationships.

Research into loneliness has generally been carried out with self-defined samples of people who responded to newspaper advertisements. Four main factors have been identified about lonely people: they are less socially responsive to others, they have lower self-esteem, they are more likely to rate others negatively and they are less likely to self-disclose than are non-lonely people (Jones et al, 1984). Self-disclosure was shown to be an important strategy in developing friendships by Miell & Duck (1986). Rubenstein & Shaver (1982) described the lonely student as one who engaged in ineffective coping responses such as watching television, overeating and oversleeping.

Rook (1982) proposed a framework for conceptualizing solutions to loneliness which emphasised modification of social settings as much as person-centred interventions. These included helping lonely individuals to develop a repertoire of enjoyable solitary activities which may enhance their well-being and being aware that the person's motivation to avoid threatening feedback about themselves may be stronger than their motivation to establish social relationships. Social skills training programmes emphasise skills in initiating social contact when they may need to concentrate on developing the person's ability to cope with criticism and conflict. Projects which bring isolated and lonely people together for a manifest purpose (e.g. receipt of free health checks) which differs from the true purpose (building social networks) seem to be more successful than befriending and visiting schemes but this is achieved at the cost of deceiving participants.

Duck (1973) used Kelly's (1955) personal construct theory to examine different aspects of adult relationships: he asked people to list the constructs they used to describe friends and compared them with constructs they used to describe strangers. Duck categorised these constructs into the following three types: interactional (behaviour such as tone of voice or facial expression); psychological (interpretations of character such as 'amusing' or 'moody') or role ('at school with me' , 'in my football team' or 'male/female'). The results showed that people used significantly more interactional and role constructs to rate strangers and more psychological constructs to rate friends.

Festinger's social comparison theory (1954) was described by Gergen (1985) as making an important contribution to our understanding of the relationship between individuals and the environment which has facilitated the development of social constructionism. Social comparison theory states that people assess their opinions and abilities by comparison with others and that, in the normal course of events, the comparators selected are those close to the individual's own ability or opinion. Taylor et al (1983) developed this theory by postulating that when people feel they are victims they make a selective evaluation of themselves. This evaluation includes downward social comparison, comparing themselves to less fortunate others so that they appear to be advantaged. This approach was applied to people with intellectual disability by Gibbons (1985).

2.2 RELATIONSHIPS IN DISABLED PEOPLE

Edgerton's powerful study "The cloak of competence" (1967) set a qualitative style for examining the lives of intellectually disabled adults leaving institutions. The people's views of themselves and their relationships with others formed a central part of that study. Edgerton built on Goffman's concept of "passing", the importance of being seen to be normal or non-disabled and the consequent avoidance of other disabled people. Bogdan & Taylor (1982) followed in this tradition, writing a biography of two people who were intellectually disabled. Both disabled people expressed dislike of the label 'mentally retarded' and pain at having been placed in an institution. Both individuals also described the problems they felt this history brought them in making relationships. One said "You can make friends by telling people about your life. Well, I made enemies by telling them about mine."(Pattie Burt's story).

Wolfensberger (1972, 1983), O'Brien (1980) and others influenced by social role valorization have intervened to try to change the social constraints experienced by people with intellectual disabilities so that they may experience a wider range of relationships. Yet when people have left hospital to live independently Flynn (1989) found that they were more likely to be lonely the longer they had been in this unconstrained living situation. In a similar vein, studies of people working in integrated settings show that physical integration does not lead to social integration (e.g.Chadsey-Rusch et al, 1989).

Helping disabled people to make reciprocal relationships with non-disabled people has been the stated goal of many services. Two examples from recent policy statements include the following recommendations.

"...to see mentally handicapped people in the mainstream of life, living in ordinary houses in ordinary streets, with the same range of choices as any citizen, and mixing as equals with the other, and mostly not handicapped members of the community." (An ordinary life, Kings Fund, 1982).

"Living in the community is not enough. People with mental handicap also need help and encouragement to mix with other non-handicapped people in the course of their daily lives. We should be creating opportunities for people to form valued relationships at home, at work or in education and in community and leisure activities." (Pursuing quality, IDC,1986).

A recent report described operational policy statements in many social services day centres as being full of "pious aspirations" for the relationships of adults with intellectual disability which were markedly different from the daily lives of those attending them (SSI report, 1989).

Removing constraints and providing opportunities may be necessary but are not sufficient to help disabled people to make a wide range of relationships. A more thorough understanding of the relationships disabled people make with one another, or the reasons why they do not make them, is required. Flynn (1989) observed that while it may be culturally normative to encourage association with non-disabled people it is nevertheless likely that people will form friendships amongst the disabled people they spend their time with. She cautioned against devaluing such relationships.

Social-ecological research was applied to the investigation of affiliative behaviour between adults with intellectual disabilities by Landesman-Dwyer, Berkson & Romer in a set of studies published between 1979 and 1984. Two strong results from these studies were that affiliative behaviour was influenced by the intelligence level of the whole social group rather than its individual members (Romer & Berkson, 1980) and that social behaviour changed between settings (Heller, Berkson & Romer, 1981).

Landesman-Dwyer, Berkson & Romer (1979) used an operational definition of friendship as pairs spending more than 10% of observed time periods together: they found 16 peer friendships from 8 group homes but do not report the total number of people living in those homes. 9 of these pairs were same-sex and half of the pairs were within a 3-year age difference. Romer & Berkson (1980) defined a friend as someone with whom the target individual passed more than 3% of their time. They found that same-sex relationships were more common but opposite sex ones were stronger. Disabled people nominated as friends individuals at a similar intellectual level to themselves but spent time with people of a different intellectual level. Friendship nominations from residents were different from friendship pairs recorded by staff, and these relationships were not stable over time.

The operational definitions used in these studies make no attempt to incorporate the subjective position and by doing so exclude an essential element of friendship according to Wright (1984). Moreover, defining friendship in terms of observed interaction takes no account of the finding with non-disabled people that experience of loneliness does not covary with amount of social contact (Rook, 1982).

Gibbons (1985) used social comparison theory to investigate the attitudes that intellectually disabled people hold towards themselves, their peers and non-disabled people. He found that intellectually disabled people living in institutions rated their abilities and attractiveness more highly than did people with intellectual disability living in the community. He thought that the institutionalised group enhanced their self-esteem by selective evaluation (Taylor et al 1983), using the people who were less able as comparators. In a study on self-concept in disabled children, Coleman (1985) suggested that those who spent some time in segregated educational settings and some time in integrated educational settings had the most realistic self-concept. If it is proved that self concept is an important determinant of friendship choice, as suggested by Zetlin & Turner (1984), then type of schooling may be an important factor influencing the relationships made by disabled people in the future.

Zetlin & Murtaugh (1988) compared the relationships of mildly intellectually disabled and non-disabled high school students. They found that the disabled students had fewer friendships than their non-disabled peers and the relationships were less stable. There was less evidence of intimacy and empathy between the disabled people, and they rarely met at weekends or in vacations. While most of the non-disabled students shared confidences only 19% of the disabled ones did so, the others interacting at a relatively shallow level. They gave an example of difficulty in responding empathically by describing a disabled woman asking a friend how she was the day after the latter had had an abortion. As soon as the friend started to discuss her experience the original enquirer changed the topic.

Social skills training is often recommended to help people with intellectual disability to make and maintain friends (eg Luftig 1988). However, Schloss & Schloss (1985) observed that the absence of a broad conceptual framework would continue to hamper developments in this area and there is little evidence of one developing. Many training packages continue to suggest that complex matters such as "assertiveness" can be covered in a few sessions (eg book 5 of the LASA pack from CMH, 1988) and propose that a course or standard curriculum will be useful for different people regardless of their history or problem.

SUMMARY

This chapter reviewed the themes in psychological investigation of friendship in non-disabled people. These were the changes in friendship across the life-cycle; the constraints on friendship imposed by social factors; the results of investigations into loneliness; the different types of constructs used to describe friends and strangers; social comparison theory and its derivative, selective evaluation, used by people who felt they were victims.

Descriptive studies of friendship in disabled people have been written by Edgerton (1967) and Bogdan & Taylor (1982). Psychological investigations of relationships in disabled people have been carried out mainly within the social-ecological framework. It was argued that these were not investigations of friendship as pairs were identified by the amount of time spent together rather than by subjective report supported by evidence of reciprocity. Some psychologists have linked concept of self as a disabled person with the relationships made and Gibbons (1985) used social comparison theory to structure his investigations.

It is possible that applying the ideas used with non-disabled people to the study of friendship in disabled people will be fruitful.

CHAPTER 3: AN INVESTIGATION OF FRIENDSHIP IN INTELLECTUALLY DISABLED ADULTS WITH VERBAL SKILLS.

This study investigated the constructs of friendship held by intellectually disabled adults attending three different day centres: half had a friend there and half did not. Both qualitative and quantitative data were obtained by using elicited and supplied constructs on which subjects rated themselves and their peers.

AIMS

1. To investigate whether people who use different types of constructs about friendship form different types of relationships.

2. To investigate the utility of social comparison theory in explaining friendship among intellectually disabled adults.

3. To investigate whether the results of research with non-disabled lonely people are relevant to intellectually disabled adults without a peer-group friend.

BACKGROUND TO THE METHOD

Studies with non-disabled adults are generally carried out using only the individuals' perspective on their friendships. It has been argued that disabled adults deserve the same rights as non-disabled people and so it was decided that a structured interview using a modified repertory grid (Kelly, 1955) would provide qualitative and comparative data without being unduly intrusive.

Studies using repertory grids with intellectually disabled people often fail to explain how it was adapted for this population. An investigation of different question formats and people who are intellectually disabled was carried out by Sigelman et al (1981). They showed that when subjects were given two choices from which to select on an either/or basis they obtained relatively high reliability and validity without sacrificing responsiveness. A similar form of questioning was described by Beail (1985) when administering a repertory grid with a moderately intellectually disabled man.

METHOD

SUBJECTS

Participants were 28 people (11 women, 17 men) from three inner-city day centres providing services for a total of 580 adults with all types of intellectual disability. The sample was derived by the following stages.

1. Staff in each day centre were asked to suggest about 20 men and women who could use abstract language, about half of whom were thought to have at least one reciprocated friendship (i.e. a voluntary association valued by both people) and half of whom were thought to have no reciprocated friendships among their peers. A total of 58 people were proposed.

2. The carers of the 58 people were sent a standard letter explaining the research project where appropriate. They were informed that their son, daughter or client would be being approached the following week and were invited to phone if they had any concerns or queries.

3. The 58 people were approached, the project described to them on an individual basis and their consent sought. No attempt was

made to persuade people who refused and 11 did so at this stage.

4. 36 people were selected from the remaining 47 based on information provided at selection interviews (described in procedure). The following criteria were used: (a) they consented; (b) they could be assigned to Group 1 (at least one reciprocated peer-group friend) or Group 2 (no reciprocated peer-group friend); (c) they could generate three distinct constructs of friendship; (d) they had a verbal comprehension of three years or more on the British Picture Vocabulary Scale (Dunn et al, 1982) and (e) their inclusion kept mean levels of verbal comprehension approximately equal across the two groups.

Following selection there was further attrition of the sample. Eight people who were selected and who agreed to take part subsequently withdrew or were missing due to illness. Seven of these were women, one a man. The four dropouts who had been classified into group 1 had a mean age of 30.5 and a mean verbal comprehension of 8.4 years. The four dropouts who had been classified into group 2 had a mean age of 33.8 and a mean verbal comprehension of 8.4 years.

The 28 people who took part in the main study are described below.

TABLE 3.1 SUBJECTS

	Group 1	Group 2
Number	14	14
men	9	9
women	5	5
Mean age	32.5yrs.	35.3yrs.
Age range	21-52 yrs.	18-49 yrs.
Mean verbal comp.(BPVS)	8.3 yrs.	6.6 yrs.
Range of verbal comp.	5.3-14.8yrs.	3.2-10.9yrs

There were no significant differences between either the chronological age or the verbal comprehension age of the two groups on a t test.

PROCEDURE

Interviews and other sessions were conducted by the author and were held in the day centre which the subjects attended.

1. Selection interviews.
Each subject had at least two selection interviews and a third if necessary. During these interviews their constructs of friendship were elicited, their friendship status checked and their verbal comprehension assessed.

Constructs were elicited by asking them to name somebody they liked and somebody they did not like and discussing how these people were different. Discussion continued until the interviewer felt that three core constructs had been elicited.

People were asked to list their friends; the peer most strongly nominated as friend was subsequently interviewed and the presence of a reciprocated friendship was confirmed if that person named as friend the individual who had previously nominated them. Peers were defined as people attending the centre who were not staff. Subjects were classified as having no peer group friends if they only nominated staff or family members, if they said they had no friends or if they named as friends people from outside the centre.

2. Familiarisation sessions.

The 36 people selected from the interviews were invited to take part in groups to ensure that all members knew one another well enough to be able to rate everybody in their familiarisation group on a repertory grid. Pairs of known friends were not included in the same familiarisation group. Most of the participants worked together and knew one another well: these groups were held to ensure nobody did not. The groups were single sex and contained six people, three who had a peer-group friend and three who did not. Groups ran twice for one hour. Their content varied according to the participants' wishes but all included the following three themes: some videotaped role play for individuals who wanted to practice greetings and conversations; discussion of their history of moves between schools, residences and day centres; discussion of words to describe disability and the general topic of friendship.

Dropouts occurred at this stage and led to two complete men's groups meeting and the third meeting with five members. One complete women's group met, one met with five members and the third was abandoned as only two of the six were able to participate.

3. Final interview.

Each person had one final interview following the group sessions. During these interviews most of the experimental data was collected on a modified repertory grid. The grid had each member of the person's familiarisation group as elements (with the order of presentatiom changed randomly between subjects); the subjects themselves were placed last. An example of a grid is given below.

TABLE 3.2: A MODIFIED REPERTORY GRID

OWN CONSTRUCTS	A	B	C	D	E
1					
2					
3					
SUPPLIED CONSTRUCTS					
1.This person has many friends/ this person has few friends.					
2. This person is intellectually disabled/ not disabled.					
3. I would tell this person my worries/ I would not.					

Score:- A for a socially desirable response
B don't know/ a bit of both (depending on item)
C the least socially desirable choice

Each subject's own constructs of friendship were placed first, followed by the supplied constructs as shown. Subjects practised by being asked to think of somebody who was not from the familiarisation group and rate them on each of the items. These ratings acted as a"buffer" to allow the subjects to hear all of the items and become familiar with the procedure, and were not recorded. Questions were repeated in a slightly different form if subjects were having difficulty understanding them. The question about being intellectually disabled was re-phrased to use words which were familiar to the subject.

~~Next the subject was introduced to the first person from their familiarisation group by being given that person's photograph.~~

Next the subject was introduced to the first person from their familiarisation group by being given that person's photograph. The subject was asked to rate the person on the grid: the interviewer replaced the photograph with that of the next group member and the procedure was repeated until all group members had been rated. Questions were re-phrased when subjects rated themselves, i.e., they were asked if they felt they had many friends or not, if they considered themselves to be disabled or not and if they felt that other people came to tell them their problems or not.

Responses coded A were for people having many friends, not being disabled and being someone they could tell their troubles to. The general principle of coding A for responses in the socially desirable direction was applied to the elicited constructs as well.

A sub-group of four people completed the grid twice with a two hour interval in between.

ANALYSIS

The independent variable was presence or absence of a reciprocated peer-group friend.

1. Qualitative study

The constructs of friendship generated by the original 36 subjects were analysed to see if there were consistent differences between the types of constructs used by people with a peer-group friend when compared with people without a peer-group friend.

All elicited constructs were listed randomly and the lists given to three professionals experienced at interviewing adults with intellectual disability. They were given a description of Duck's (1973) three types of constructs, i.e., Psychological, Interactional and Role, and asked to classify them into categories where they could, leaving others in a "not sure" category.

2. Comparative study

Four dependent variables were examined.

- Rating of self and peers on the dimension disabled/not disabled.
- Total ratings of self on own and supplied constructs.
- Total ratings of peers on own and supplied constructs.
- Rating of willingness to self-disclose.

Data for these variables were obtained from the grid ratings made by the 28 subjects who took part in the familiarisation sessions and final interviews.

RESULTS

The following questions were asked of the data.

1. Did individuals from the two groups generate different types of constructs of friendship?

2. Were the grid ratings reliable?

3. Was there a difference between the way people in each group described themselves and their peers with regard to disability?

4. Were group 2 people similar to lonely non-disabled people?

1. Did individuals from groups 1 and 2 generate different types of constructs?

The three raters independently classified 44% of constructs into the same categories; the following analysis only concerns those constructs which raters agreed. The proportions of construct types used by students rating strangers in Duck's (1973) study have been converted into whole numbers and appended to the table for comparison.

TABLE 3.3: CONSTRUCT CLASSIFICATION

----------------	Inter.	Psychol.	Role	Other
Group 1	8	3	11	0
Group 2	6	4	13	3
Totals	14	7	24	3
Duck's subjects' ratings of strangers..........	(17)	(9)	(16)	(3)

There was no difference between the types of constructs used by people from groups 1 and 2 on a $\underline{x}^2$ test.

2. Were the ratings on the grid reliable?

The four people who completed the grid twice had a mean verbal comprehension of 6 years on the BPVS, range 3.6 years to 8.3 years. The consistency of the four subjects' ratings on their own constructs was a mean of 83% same rating (range 72% to 94%);

their consistency on the supplied constructs was a mean of 76% same rating (range 75% to 79%).

3. Was there a difference between the way people in Groups 1 and 2 described themselves and their peers with regard to disability?

3.1 A comparison of self-rating on the dimension intellectually disabled/not showed that Group 1 subjects were significantly more likely to describe themselves as being not disabled than were Group 2 subjects (Fisher exact probability Test, $p<0.05$).

3.2 A comparison of the ratings of others on the dimension on disability showed no significant difference between people in Groups 1 and 2.

These results show that Group 1 members were more likely to see themselves as non-disabled but they were not more likely to see other people as being disabled.

4. Were Group 2 people similar to lonely non-disabled people?

4.1 A comparison of the total positive and negative ratings of others used by Group 1 and 2 subjects showed no significant difference.

Unlike lonely non-disabled people, Group 2 subjects were not more negative about other people.

4.2 Comparison of self ratings in Groups 1 and 2.

A comparison of the self-ratings on own and supplied constructs showed a significant difference ($\underline{x}^2 = 18.7$, df =2, $p<.001$) with

Group 1 subjects rating themselves in the socially desirable direction more often than Group 2 subjects.

Analysis of the results concerning self-disclosure showed a difference which did not quite reach significance between the willingness of group members to tell others their worries ($\underline{x}^2$ = 3.82, df = 1, $p<.01$: $\underline{x}^2$ = 3.84 is required for $p<.05$), people with a peer-group friend showing a tendency to say that they would self-disclose.

Group 2 subjects were similar to lonely non-disabled people in their tendency to avoid self-disclosure and in their use of significantly more negative self-ratings.

DISCUSSION

This investigation described the expectations of friendship and perceptions of self and others held by two groups of intellectually disabled adults, those with and without peer-group friends. The presence or absence of a friend was experimentally defined. This facilitates comparison with other experiments which use a similar definition but also limits the investigation to a study of particular types of friendship.

Adults from three different day centres were included in the study, increasing the generalizability of the results. However, the necessity to work with verbally skilled people who were willing to volunteer meant that the sample was far from representative. The 11 people who initially refused to take part and the 8 people who dropped out subsequently are almost as big a group as those who took part. The experimenter spent time in the day centre, taking tea and lunch breaks among the disabled people in order to become a familiar face and it was not felt that that was behind the high rate of refusal. For some people it seemed that the issue of friendship was difficult and painful, for others friendship was seen as unimportant. For example, one person described having epilepsy and facial neuralgia and felt that those were the issues she wanted to spend time resolving.

All of the people who dropped out after agreeing to take part did so when the familiarisation sessions were scheduled. For a few this was due to timetable clashes which were unforseen or because of absence on holiday or sickness. However, for the majority it seemed that the familiarisation sessions were aversive. They had been explained and the people had apparently agreed but it transpired that they were unwilling to sit in a room with the experimenter and five peers who were not of their choosing, even though they had enjoyed the individual discussions with the experimenter. Rook's (1982) observation that many lonely people are motivated to avoid threatening feedback rather than to establish social relationships may have been relevant here.

Interpretation of the results should also be tempered by the difference in verbal comprehension between the two groups. While this difference was not statistically significant the net effect of the dropouts was to add to the verbal advantage of Group 1 subjects.

Inspection of the elicited constructs of friendship allows speculation about the quality of the subject's relationships. Constructs used frequently included the following: talks nicely--shouts and swears, and listens--talks too much (interactional constructs); kind--nasty (a psychological construct); takes me out--does not take me out (an interactional construct). Constructs such as 'is a comical person--is no fun' occurred but were rare. Most of the constructs which could be agreed by raters were classified as either interactional or role. The hypothesis that people with and without a peer-group friend would use different types of friendship constructs was not supported. The friendships discussed by the whole sample were described by the types of constructs which Duck (1973) found students used to describe strangers; they rarely suggested the sort of interdependence which Wright (1984) regarded as a defining characteristic of friendship.

Consideration of the constructs from these perspectives suggests that most of the people interviewed experienced a relatively superficial relationship regardless of how long their friendship had been in existence. This is consistent with Zetlin & Murtaugh's (1988) observation on the lack of intimacy and empathy in many interactions between intellectually disabled adolescents, and with the overall findings from research into the relationships and social lives of these disabled people.

The development of a theoretical understanding of the quality of friendships among people with intellectual disability could profit from reference to social-emotional developmental models (eg Youniss 1980). Superficial relationships would be predicted if, for example, peoples' social-emotional maturity resembled that of an eight year old.

The second set of results concerned issues derived from social comparison theory, specifically subjects' reactions to the experience of stigma. This investigation found that people with an intellectual disability who had a peer-group friend were more likely to describe themselves as non-disabled than people who did not have a friend. However, they were not more likely to describe their peers as being disabled. This confirms part of the social comparison theory prediction, that people in stigmatized or victimized groups cope by distancing themselves from the group. However, they did not achieve this by rating other people as more disabled or disadvantaged and so the phenomenon of downward social comparison was not observed.

The last set of results concerned the investigation of issues arising from loneliness research. Results fell into two areas: ratings of others and ratings of self, including willingness to self-disclose. Other studies have found that lonely non-disabled people rate others more negatively than do non-lonely people. This was not found between the two groups in this study and so in this respect Group 2 people were not like lonely non-disabled adults.

Similarly, other studies show that lonely non-disabled adults have low self-esteem. Subjects without a peer-group friend in this study were more likely to rate themselves negatively on every dimension used. This included rating themselves negatively on the three constructs they had said described characteristics which were important to them in a friend. This is an unconventional way to measure self-esteem, but one which has face validity. Results from the current study suggest that in this respect disabled and non-disabled adults are alike.

The result on self-disclosure escaped statistical significance but suggested a trend. The general reluctance of the whole group to disclose personal matters to their peers was striking and the frequency with which people responded that they had been told to reserve such discussions for staff was a cause for concern. If self-disclosure is important in forming and strengthening friendships than such sharing should not be discouraged without good reason.

CONCLUSIONS

Results suggest that many people in this study had superficial friendships and a general distrust of their peers. The results of investigating social comparison theory were mixed but they do suggest that there are consistent effects associated with self-concept and not merely individual differences. Adults without a peer-group friend in this study showed sufficient similarity to lonely non-disabled people to make the application of interventions for the latter group to the former worth considering.

PART III

CHAPTER 4. PROFOUNDLY INTELLECTUALLY DISABLED ADULTS: CONCEPTUAL ISSUES, PROFOUND DISABILITY AND A SELECTIVE REVIEW OF INTERACTION STUDIES.

Chapter 1 reviewed evidence about the limited social lives of most people with intellectual disabilities. It also introduced social constructionism as a philosophical assumption influencing psychological enquiry. This chapter examines literature relevant to social interaction in adults with profound intellectual disability in order to provide a theoretical base for a set of studies into carer-client interactions which were carried out in 1988 and 1989. These are reported in chapters 5,6,7, 8 and 9. The main purpose of these studies was uncovering themes in carer-client relations which could help carers to interact with their client more effectively. It is assumed that profoundly disabled people have social needs similar to those of other people, although their high levels of dependence may mean that their needs are greater.

Some reservations were expressed about the supportiveness of staff relationships, as they change frequently. However, adults with profound intellectual disability are more likely to be cared for by staff than by families because of their multiple needs. Research in this area was reviewed in the introduction; it can be summarised as follows. The amount of staff contact provided and the amount of informative speech used with residents is associated with good client outcomes. The most disabled people and those who display maladaptive behaviours receive the least staff contact. Mean duration of each staff contact has been around 30 seconds to one minute. The amount of time profoundly disabled children passed interacting with staff and the number of child initiations which were responded to by staff remained low despite staff:client ratios of 1:3 or better. These last studies suggest that staff find it difficult to interact with profoundly intellectually disabled people for any length of time.

The secondary purpose of this review and subsequent investigations was to contribute to a new conceptualisation of profound intellectual disability in adults. The British Psychological Society published a set of papers under the general title 'Models of Man', edited by Chapman & Jones (1980). This set of conference papers provide guidance about the way that psychologists view conceptual models and their utility.

One point to emerge is that descriptive models are useful stages towards the development of prescriptive models which allow experimental test, although Richardson (1988) argues that psychological experiments are very rarely structured to simultaneously eliminate rival theories. Warr (1980) suggested that models, theories and paradigms all serve to organize thinking and action, proposing that they do so by being conceptual sieves or moulds. The sieve functions by allowing some ideas to pass through but rejecting others, while moulds help to shape the ideas which filter through.

Jahoda (1980) suggested that a model is a conceptual tool which assists people to think about reality. Wood (1980) felt that theories rarely give the teacher or parent information about what they should do. They function after the event to explain why one approach succeeded when another did not.

The limited life-expectancy and 'developmentally young' status of profoundly disabled people may have contributed to the trend for research to be carried out primarily with children (for example Glenn & Cunningham, 1984; Ware & Evans,1986). Other projects have combined children and adults (Landesman-Dwyer & Sackett, 1978; Burford,1988; Hogg et al 1988) as if the authors perceived no distinction. Burford's paper, for example, refers to people with disability as children regardless of their age.

Hogg & Sebba (1986) state that there is no agreed theoretical or procedural framework to guide investigation of this group. They propose that the framework provided by studies of normal child development gives a reference point or context for studying people with multiple disabilities. They suggest that studies of child development have changed considerably since Baumeister (1967) expressed his view that to understand disabled people they should be studied in their own right. Murphy (1985) objected to the use of a child development model with this group as the degree of self-injurious behaviour can be far more severe than the head-banging of non-impaired infants and seems different in nature. Hogg & Sebba respond to this with the following:

"It is also clear... that extensive brain damage, epilepsy and failures of social development can disrupt sequences of development and may preclude further advances in a given area. This state of affairs, however, should not be seen as a limitation to the applicability of the developmental frame of reference, but a pointer to psychological, social or medical remediation that places the child more firmly within the context."(v.1,p220).

This position is not falsifiable. All instances of failure to match the behaviour of a profoundly disabled person against the framework of child development are explained as evidence of specific damage which should be remedied. Such a model is of questionable utility.

Kiernan (1984) discussed the role of developmental and difference theories in the field of intellectual disability, suggesting that as more becomes known about an aspect of disability the more a difference theory is supported. Kiernan was commenting on the debate between the view that people with a matched mental age score will be similar in their cognitive performance (the developmental position) and the opposing view that there are fundamental differences between disabled and non-disabled people which are not explained by mental age scores, since they are arithmetic composites which communicate relatively little about an individual's capabilities. Baumeister (1987) stated that this controversy remains at the heart of our conception of intellectual disability and felt that future intervention and policy development will depend upon its resolution.

This chapter reviews the literature in four sections. The first two sections examine existing psychological models and theories which could contribute to a conceptual framework of profoundly disabled adults: theories of socio-emotional development in children are discussed first, followed by theories of social experience in adults. The third section discusses theories, ideas and experiments with profoundly and multiply disabled people. The main themes are discussed in a final summary section.

4.1 SOCIO-EMOTIONAL DEVELOPMENT IN YOUNG CHILDREN.

In 1973 Brazelton developed the Neonatal Behavioural Assessment Scale which examines the infant's level of control over its physiological states. The neonate's developing control over transitions between sleep and alert wakefulness and between crying and being aroused is noted. Brazelton assumed that the alert state was necessary for the infant's social capacities to be expressed. An interest in level of arousal is also found in Sroufe (1979) and Als (1982).

Brazelton (1982) later concentrated on the process of rhythmic interaction/ non-interaction, seeing this as the key behaviour which parents establish when interacting with their child. Smiles, vocalisations and touch are all exchanged within this rhythmic structure and changes in tempo have to remain within limits imposed by the structure if the child's arousal is to be maintained at an optimal level. Usually, a faster pace means reduced demand on the child and vice versa.

Bruner's (1975) influential paper describes his view that the linguistic development of children is facilitated by the assumptions and interpretations made by their parents. This led to a debate about the role of infants in interaction, Trevarthen (1975) delineating the opposing view that babies are equipped from birth with a mechanism which helps them to express their own personhood. Bruner's view was supported by Kaye (1982) who wrote: "The exaggeration or overinterpretation of infant capacities in the past decade has held back our understanding of basic issues in human development."(p31). Kaye's analysis of mother-baby interactions during feeding found no evidence for the suggestion that to predict an infant's development it was necessary to observe the mother-infant pair in interaction. Factors such as maternal education were sufficient to explain the variance in his sample of babies under 6 months.

Tronick (1982) suggested that the affective system is the only system available to the infant for establishing joint regulation with its carer. He proposed that successful regulation of joint interchanges results in normal development and that "failure to establish joint goals or shared time derails infant and adults from the normal developmental track....it is the cumulative iteration of the exchanges that structures the child." (p1). Tronick also saw the carer's role as including sensitive non-sharing as well as sensitive sharing, as it is sometimes possible to demand a little more from the infant without disrupting their affective state. Differences in motivation between interactants has not been mentioned frequently but was raised by Durkin(1987), who suggested that analysing failed interactions rather than harmonious ones might be useful.

Sroufe's(1979) theory of socio-emotional development laid emphasis on the role of tension and arousal in emotional expression. Here, tension is not seen as an aversive event but something which the child would actively seek at times. It is a concept amalgamating physiological arousal with cognitive evaluation. For that reason it is seen by Dunn (1982) as being a useful model which articulates the relation between cognition and affect.

Sroufe's (1979) theory of social-emotional development contains a description of eight developmental stages which are said to be normative rather than invariant. The "passive stimulus barrier" describes the infant of 0-1month who is relatively invulnerable to external stimulation. The second period of "turning toward the environment" from 1-3months was described as a period of vulnerability as the infant is open to stimulation and only has preadapted devices for the modulation of tension. Here Sroufe seems to be talking about the way a young infant fixates on a highly stimulating object, apparently unable to inhibit looking and not yet sufficiently co-ordinated to be able to turn away.

The third period is described as "positive affect", the 3-6month old baby becoming increasingly responsive, developing the ability to laugh and to take part in reciprocal exchanges. This leads to the period of "active participation" where the 7-9 month old infant participates in social games, starts initiating interactions with caregiver and is highly excitable. Engagement and pleasure at mastery grow; the infant will make persistent attempts to elicit expected social responses from somebody behaving unconventionally.

Later periods are the "period of attachment" (9-12 months); the "practicing phase" where emotionally ebullient infants actively explore and master aspects of the environment, and the "formation of self-concept". The last two phases are described in association with the infant's development of walking and increased physical separation from others. If that is the case it invites the question of how failure to develop independent mobility influences the development of a concept of self.

Bowlby's (1988) work on Attachment Theory has been one of the most influential approaches to understanding affective development. Two components are relevant:
a) the creation and maintainence of intimate emotional bonds is assumed to be controlled by a cybernetic system within the central nervous system which is influenced by working models of the self and attachment figure(s) in relation to self, and
b) attachment is powerfully influenced by the way that the child is treated by the parents, particularly by the mother-figure.

This theory proposes a system through which socially constructed understanding of self and others may come about. The importance of children forming a strong relationship with a carer when they are between 9 and 12 months has also been stressed by Bower (1979), Sroufe (1979) and Schaffer (1989).

4.2 SOCIAL EXPERIENCE IN ADULTS.

Few of the theories of human behaviour in non-disabled adults are useful to our understanding of people with profound developmental disability. This section discusses three approaches which may make a contribution. The first is a discussion of the philosophy of Martin Buber (1958); the second is the contribution of G.A.Kelly (1955); the final theory is that proposed by Maslow

(1970).

MARTIN BUBER.

Social constructionism was described in the introduction as an assumption influencing current psychological thinking. Social constructionists feel that the important level of analysis is the way that people interact with one another because people construct their selves through these interactions. Pfuetze (1961) brought together the work of G.H.Mead and Martin Buber as he felt that both had made complementary statements about the social nature of humanity from different standpoints. Mead was a scientific, social psychologist. Buber was a German religious philosopher and academic who wrote from 1923 to 1967.

Pfuetze (1961) was concerned with the social self which he saw as the product of social or interpersonal relations involving meeting, symbolic interactionism or dialogue. He felt that in understanding the social self Mead provided the scientific floor while Buber provided a metaphysical ceiling. Pfuetze described their work as follows: "Both Mead and Buber are saying...that the essential and constitutive character of human life and selfhood is something that takes place between one person and another in a society of persons." (p6).

The following summary of Buber's contribution is based on Buber (1958), Pfuetze (1961), Diamond (1960) and an edited set of comments on Buber's work with replies from Buber (Schlipp & Friedman, 1967).

Buber described two fundamental dimensions of human experience, the I-it and the I-thou relation. These are seen as originating in the physical and human worlds respectively, providing people with two attitudes with which they confront the external world: the functional and the personal. The I-it relation concerns manipulative adjustments but also describes a detached approach to people or objects which involves only parts of oneself. The I-thou relation is personal, empathic,intuitive and involves the whole self.

Buber originally characterised I-thou as mutual and reciprocal, something which refreshes the spirit and gives reality and meaning to life. I-thou exchanges are described as "...moments of revelation. Revelation brings ... no precise content. But it brings assurance as to the meaningfulness of life." (p156, Pfuetze,1961). However, I-thou relation between individuals and animals, works of art or nature has created debate on how mutuality or reciprocity are expressed in these cases. Buber described the relation between teacher and pupil or pastor and parishioner as I-thou at best despite their lack of mutuality. He described the I-thou relation with an animal as reciprocal when animals respond to people who approach them with a sense of partnership. Perhaps the most difficult of Buber's arguments concerned human relations with nature. He responded to critics as follows.

"It is part of our concept of a plant that it cannot react to our action ...Yet this does not mean that here we are given simply no reciprocity at all:..there is a reciprocity of the being itself...That living wholeness and unity of the tree, which denies itself to the sharpest glance of the mere investigator and discloses itself to the glance of one who says thou,..Our habits of thought make it difficult for us to see that here, awakened by our attitude, something lights up and approaches us from the course of being." (p708, Schlipp & Friedman, 1967).

Buber did not use "respect" or "dignity" although these seem to be concepts which are included when approaching someone as 'thou'. Respect and dignity are words which have been used repeatedly by Wolfensberger (1972) and followers such as Bercovici (1983) in their advice about ways of interacting with intellectually disabled people and their discussion of keystones of service delivery. Buber's philosophical anthropology is consistent with the social constructionist position currently held by many psychologists; it is consistent with the advice of people writing about service provision and appropriate ways to approach fellow humans, and it may provide a meaningful model of interaction for staff working with profoundly intellectually disabled adults.

G.A.KELLY.

Kelly's work concerned the structure of personality and the relationship between self and others in non-disabled adults. This is relevant to the needs of intellectually disabled people who have language, as was seen in chapters 2 and 3. Two themes from his theory may also be applied with profoundly intellectually disabled adults. The first is people anticipating the behaviour of others, expressed in the Fundamental Postulate. The second is that people need to understand some aspect of the other person's outlook before they can be involved in a social process with them: this is the sociality corollary.

The Fundamental Postulate states: "A person's processes are psychologically channelized by the ways in which he anticipates events." (p103, Kelly, 1955). Anticipation and prediction seem to be very relevant to profoundly disabled adults who are often described as fearful and defensive when people approach them (for example, Green-McGowan & Kovacs, 1984). If rough handling has been the person's main experience of contact with others then anticipation of this is likely to dominate their psychological processes.

However, if careful interactions are more frequent then the profoundly disabled person may start to predict the behaviour of the other person and so join with them. This is essentially the basis of Co-active therapy (Van Dijk, 1977) used with deaf-blind children. The use of social routines or 'formats' was also described by Bruner (1975) as facilitating communication between infants and mother-figures, but Kelly's theory makes this proposition fundamental to understanding humanity. The following statements from Kelly (1955) are relevant to understanding this process in profoundly disabled people.

> "Now what about prediction?....We look at the undifferentiated stream of circumstances flowing past us, and we try to find something about it which repeats itself....If we fail to find such a property, we are left swimming in a shoreless stream...Thus the first step in prediction is to get hold of a solid fistful of something to predict."(p120).

This provides a reason for interacting with somebody profoundly intellectually disabled despite apparent unresponsiveness.

Kelly's (1955) Sociality Corollary states that : "To the extent that one person construes the construction processes of another, he may play a role in a social process involving the other person." (p95) This corollary proposes that social contact will be facilitated if the interactant has gained some understanding of the person's outlook; it also proposes that no meaningful interaction will occur without it. There are many echoes of this position in Buber's writings when he describes empty social contact.

A.H.MASLOW

As services for children and adults with developmental disability in Britain become increasingly needs-led (1981 Education Act, 1986 Disabled Persons Act) this theory is worth reconsidering for its analysis of levels of human need. Maslow (1970) emphasised that most human acts spring from more than one source or level of need and that motivation is a fluctuating and complex state. He proposed that in many cases needs or wants seem to arrange themselves into a hierarchy of prepotency but that he did not believe that the sequence was invariant.

Most relevant to the needs of profoundly disabled people may be examination of the two most essential levels of needs. The basic needs are for food and physical comfort, which could include assistance to move or change position in physically disabled people. The next level looks at safety needs, the need for stability and dependency (or, to use Bowlby's phrase, attachment) and freedom from fear,anxiety or chaos. In freedom from chaos we can see another perspective on levels of arousal, of not feeling 'disorganized' to use Brazelton's word. Safety needs are relevant to the person who is fearful or defensive as described above.

4.3 STUDIES WITH PROFOUNDLY INTELLECTUALLY DISABLED PEOPLE.

Glenn & Cunningham (1984) described their studies into auditory preferences in severely, profoundly and multiply disabled children. At around a developmental age of 9 months children studied were able to demonstrate choice and consistent preferences for different speech patterns. They preferred rhymes sung rather than played on an instrument, they preferred rhymes with correct words to those with nonsense syllables, they preferred rhymes to a repetitive tone and they preferred the sound of an adult speaking to them rather than to another adult. Children around a developmental age of 5 months demonstrated an ability to use the equipment and consistently chose a rhyme over no sound. However, they did not make any consistent choices between different sound stimuli. The authors concluded that profoundly disabled children are active processors of environmental stimuli if they are provided with equipment and opportunities which allow them to express this.

Landesman-Dwyer & Sackett (1978) studied profoundly disabled children and adults living in an institution who were non-ambulant. The study was a longitudinal evaluation of the effects of physical and social stimulation on the behaviour of 16 people whose overall performance on the Bayley Scales of Infant Development was less than 6 months. That assessment was done 4 times: 12% of items were passed each time, 55% of items were failed each time, while 33% of items were passed some of the time. The experimental group was reassessed following the stimulation programme. There was no significant effect of stimulation on their mean developmental age on the Bayley.

Regular stimulation sessions did show significant effects in other areas. There was a significant change in the pattern of sleep/wakefulness. The experimental group slept the same amount as controls (about 12 hours in 24) but did so in fewer periods, developing a mid-day sleep and reducing the total number of sleep periods. Experimental subjects also showed significant change in alertness, reducing the time spent in low level activity from 8 to 5 hours and increasing the time spent in moderate levels of activity.

Landesman-Dwyer & Sackett (1978) measured various behaviours during stimulation sessions, afterwards on the ward and 2 months after the sessions ended. They developed meaures of behavioural complexity, environmental contact, vocalization, looking, mouthing, and fixed action sequences (which included stereotyped behaviours, reflexive responses and seizure activity). Significant change on these measures was not accompanied by change in attainments on the developmental assessment.

Not every profoundly disabled person displays stereotyped behaviour but it is negatively correlated with intelligence (Baumeister, 1978; Oliver et al 1987). The behaviours occur in such a wide variety of forms that they are easy to describe but difficult to define. They are classified differently. Hogg & Sebba (1986) and Hogg et al (1988) include stereotyped behaviours in general discussion of "behaviour problems", while Landesman-Dwyer & Sackett (1978) included stereotyped behaviour with seizure-like activity and reflexive responses in their category of Fixed Action Sequences. Murphy & Wilson (1985) reviewed studies of self-injury, some of which distinguish between that and stereotypy while others describe self injurious behaviour as a special case of stereotypy.

Baumeister's (1978) article remains a useful guide to stereotyped behaviours. These generally have a long history in the individual's repertoire and are often of early onset. They seem to be maintained by social factors and to serve communicative or signalling functions in some cases (this has been developed by Iwata et al, 1982). Baumeister felt that stereotyped behaviours may serve a coping function for individuals responding to frustration. He suggested that some stereotyped movements are mediated by neurological events. Baumeister examined evidence for the hypothesis that the movements are "self-stimulating" but concluded that the concept was too general to be useful and that a convincing argument could be made for the movements being stimulus depriving, since disabled people are less responsive to environmental stimuli while so engaged. Despite this the description of stereotyped behaviours as "self-stimulating" remains common (see Murphy & Wilson, 1985).

Baumeister(1978) concluded that environmental enrichment usually brought decreases in the frequency and rate of stereotyped movements and that behavioural consequences which reduce the overall rate usually do so by increasing the amount of time spent in pauses between bursts. Research on attachment with primates combined with research about profoundly disabled people led Baumeister to conclude that stereotyped movements have their origin in the disruption of interactions that non-disabled infants normally have with their mother-figure. Although Baumeister did not propose a model of profound disability his research suggests that stereotyped behaviours should have a place in any conceptual model which is developed.

Als (1982) carried out a longitudinal study of the development of interactions between three mother-infant pairs. One was a normal healthy baby, the second was born blind but with no other impairments and the third was a multiply physically disabled infant. The development of interaction with the blind infant proceeded at about the same pace as that of the normal baby although at each stage the range of affect shown by the infant was more restricted than that of the normal child. Interacting with the multiply disabled child developed more slowly and was more dispiriting for the mother. The main stages of that development between the last pair are described, as this illustrates the way that Als relates physiological state to interaction strategies. Although the child's intellectual status was not known the effect of the motor disability on the infant-mother interaction is relevant.

When the mother stimulated the 16 day old infant he initially moved from 'unavailable' to 'high monitoring' but then he started to mouth and gasp and gag. He subsequently remained unavailable despite his mother's efforts, sinking into an exhausted, averted position when she gave up. At 40 days the mother approaches more slowly as if afraid to unbalance his steady state. She keeps the input low but as he begins to respond his breathing becomes laboured and disorganized again. At 75 days they are more involved with each other but still at a low level with any raised arousal resulting in him regurgitating food. Following regurgitation he is now able to return to an organized state with mother's help.

At 4 1/2 months they interact with smiles, vocalisation and imitation from mother; however, he builds up to become disorganized again, ending by crying. The exchange was seen as a breakthrough in interaction by the researchers who observed that it coincided with mother's increased confidence and pride in herself and her child. Even so, by 6 months the researchers felt that the mother's expectation of failure was accumulating and that she was finding it tiring to continually provide the infant with the organization and energy he needed if he was to be at anything other than a low arousal state.

Based on these detailed case studies Als (1982) suggested a modification of developmental stages in the face of "biological violation". These described the successive development of autonomous control in a number of areas: physiology, orientation and arousal, play and finally affective exchanges. Als discussed the observed damage to the interactive feedback system between parents and disabled infants, suggesting that their acceptance of the distortion may help the dyad to work towards accomplishing joint developmental tasks.

There have been a number of studies of interaction between parents and intellectually disabled infants (for example, Berger & Cunningham, 1983; Mahoney & Robenalt, 1986) and between teachers and profoundly hearing-impaired children (Wood et al 1982) which have reached similar conclusions. These are that people interacting with disabled children tend to use language which is more directing or controlling and tend to be less responsive to child-initiated communications than are parents of normally developing children. Wood & Wood (1984) showed that highly controlling conversational moves result in deaf children talking less and that more responsive strategies enable the same deaf children to speak more. They also emphasised the formidable demands being made on the conversational skills of teachers and the wide variation in style which occurred. They discussed the complicated ebb and flow of conversational control observed when experienced teachers combined leading with responding in a dialogue and concluded that an analysis of levels of control was not the only issue.

Mahoney's (1988) analysis of maternal style and the responses of 1 to 3 year old intellectually disabled children showed that maternal style accounted for 73% of the variance in the children's non-verbal communication and 53% of the children's verbal communication. He felt that previous research had ignored wide ranging differences between the style of mothers particularly on the dimension of directiveness versus responsiveness. This style was significantly related to mother's socio-economic status. He found that children were much more likely to communicate verbally when their mothers were responsive to both verbal and non-verbal communication, when the conversational topic was child-orientated and when the mothers requested that the child engage in conversation rather than perform tasks. Children with the highest expressive language scores had mothers who displayed these skills. The level of language functioning was unrelated to their cognitive and sensorimotor functioning or their health status.

Mahoney assumed that the association between child communication and maternal style showed that there was a reciprocal relationship between maternal and child behaviour but he added the following rider: "Given the results from this study, however, it is questionable whether all of these natural accommodations are optimally suited to promoting the development of retarded children"p358.

Rogow (1982) described the use of nursery rhymes as having helped 10 blind, mutiply disabled children to develop social interaction. The descriptions suggest that some but not all of the children may have been profoundly intellectually disabled: their chronological ages were from 1 year 3 months to 6 years 5 months. They were assessed on their ability to signal that they wanted to initiate or maintain a social routine, on their spontaneous use of social signals and on their ability to imitate. The author reports that all children improved as a result of the intervention, providing descriptions of findings with different children under different headings. This seems to be an interesting idea worthy of more systematic study.

Bunt (1985) evaluated the effects of music therapy with children of different ages and different levels of intellectual disability. Children were included if they had particular difficulties integrating socially with their group. The results of this work, an unpublished PhD thesis, are too numerous to cover. Bunt developed qualitative measures of imitation, of 'interruptive' behaviours which included stereotypies, of turn-taking, initiative, imitation and vocalization. Most of these showed change during the sessions. Turn-taking was the one behaviour which showed generalization to the classroom and maintenance on follow-up.

Burford (1988) carried out a study of rhythmic actions with profoundly disabled children and young adults. Five different rates of rhythmic approach used by parents and carers were identified and described with a presumed interactive intention. These were categorised by the author who inferred the motive of the interacting adults from comments they made about what they were doing during the interactions (although following Buber's position an interaction would not have an I-thou quality if it was accompanied by a running commentary). Two of the five rhythmic cycles were found to be used by parents of 4 to 8 week old infants in Scotland and Nigeria (tapes provided from another study by Trevarthen) and so the author suggests that there are universal rhythmic patterns which transcend culture. Burford reported that the profoundly disabled people also showed some of these rhythmic actions in response to the carer. She ascribed affect to these cycles without explanation. The disabled people apparently use rapid cycles to express enjoyment.

The report describes micro-analysis of videotaped sessions but gave no interobserver agreement data and little quantitative information such as how many profoundly disabled clients displayed which action cycles. Methodological issues are discussed in detail in the next chapter but a quotation from one book on the topic is pertinent here. "In observational studies...it becomes especially important to convince others that what was observed does not unduly reflect either the investigator's desires or some idiosyncratic world view of the observer." (Bakeman & Gottman, 1986, p71). Burford's comments about the striking regularities in rhythmic action which she observed and the precise timing she gives to them suggest that this could be a new contribution to the field if the problem of observer reliability were addressed.

The final set of studies were carried out by Sternberg et al (1983), Sternberg et al (1985) and Sternberg & Owens (1985). These papers concern the application of co-active therapy, a technique developed for use with deaf-blind children who are not intellectually disabled (Van Dijk, 1977). This involves the keyworker and child moving together in repeated patterns devised either to follow the child's natural movements or using familiar actions such as dressing. Sternberg and colleagues showed that these techniques could be used with profoundly intellectually disabled adolescents and adults. They established preliminary communicative awareness behaviours in four people and achieved partial success with a further three. They emphasised the very preliminary nature of their work.

Sternberg & Richards' (1989) conceptual article discussed the salience of levels of arousal or state when teaching individuals with profound disabilities. They suggest that examining whether there are fixed or variable cycles of state changes in profoundly disabled people could yield useful information. They propose a scheme for assessing levels of state in profoundly disabled people which combines aspects of Landesman-Dwyer & Sackett's (1978) scheme with one devised for infants by Campos & Brackbill (1973). They suggest that research questions should focus on two areas: an investigation of the factors which account for variation in levels of state and investigation of how and under what conditions levels of state can be modified towards greater receptivity.

SUMMARY

This chapter discussed the current dominance of the model of child development in describing people with profound intellectual disability and questioned its utility. It has been suggested that developmental models give way to difference models as researchers discover more about an area. The role of models in psychology is one which is debated. Descriptive models are useful if they organize thinking by sieving and moulding new ideas. Predictive models were goals for developed areas of study but this is not currently the case in research into profound intellectual disability.

Studies of socio-emotional development in children were reviewed for perspectives on profoundly disabled people. The infant's level of arousal and patterns of rhythmic exchange with their carer were concepts influencing a number of studies. Debate about the contribution of the infant and the contribution of the carer to interactions was outlined. Tronick's view that the affective system allows the infant to regulate interactions was described: discussion of the control of intensity of affect links to the concept of arousal. The developmental schemes proposed by Sroufe and Bowlby were outlined: the former placed tension and arousal in a central position while the latter linked the infant's sense of self (derived from the way their mother-figure treats them) with their ability to form emotional bonds.

Tronick's idea that a social self is structured by cumulative iterations of exchanges with a carer is a statement of the social constructionist position. For the exchanges to be meaningful Buber would say that they should be done wholly, personally and allowing the person to step forward to meet you. Maslow's theory suggests that the basic needs should be addressed before such meaningful exchanges can occur. Kelly and Bruner emphasise the importance of repetition and predictability: Kelly's theory also points to the necessity for carers to have some understanding of the profoundly disabled person's experience. These perspectives were discussed in the light of many profoundly disabled people's fearfulness and defensiveness.

Two sets of studies were reviewed which show aspects of profoundly disabled people's behaviour. Glenn and Cunningham's studies of auditory preference describe the choices which children at different developmental ages can make, as long as the equipment is set up in a way that facilitates their responding. The study by Landesman-Dwyer & Sackett (1978) is rich in information about children and adults who are most profoundly disabled. It demonstrated the variability in their responding. The effects of a stimulation programme on many aspects of behaviour including level of arousal were demonstrated.

Stereotyped behaviour was seen as an important facet of profound disability and one which any model should take into account.

Als' report of a mother trying to interact with a child whose physiological control was poor illustrated the difficulties experienced by both parties. The comment on the mother's accumulating sense of failure and her exhaustion at continually providing the infant with the organization and energy he needed was particularly important. An understanding of interactions between profoundly disabled people and carers will require equal attention to the needs of both parties.

Studies which show the increased likelihood of directiveness when people interact with disabled children, and others showing considerable within-group variability on this dimension, provide another perspective on the study of interaction.

Intervention studies suggest that the following may facilitate interaction: nursery-rhymes, drama involving rhythmic movement and touch, co-active therapy and music therapy. The latter has an effect on interactive turn-taking which generalises and endures.

Sternberg & Richards documented the variability found between people and in the same people from day to day; their conceptual article on levels of state or arousal in profoundly disabled people suggests an interesting new direction.

CONCLUSIONS

This review has described the wealth of psychological information which is relevant to profound disability. The work described contributes different perspectives on the carer-client relationship and its meaningfulness.

It was suggested in the introduction to this chapter that the high levels of dependence found in adults with profound intellectual disability makes their social needs greater than those of people with other disabilities. It therefore makes sense to consider the behaviour of people with profound disability as being socially constructed, not located within the individual alone. It is likely that the relationship with a keyworker plays a significant part in that process and so it is this which will be the focus of detailed investigation in the following chapters.

CHAPTER 5: INTRODUCTORY OVERVIEW OF THE SET OF STUDIES INVESTIGATING INTERACTIONS BETWEEN STAFF AND ADULTS WITH PROFOUND INTELLECTUAL DISABILITY.

The studies of interaction described in chapters 6, 7, 8 and 10 were carried out between October 1987 and March 1989. They are an exploration carried out with staff who volunteered to take part. The pilot study and three subsequent investigations described strategies which staff were using while interacting and investigated two of them in detail.

This overview describes the way in which subjects were obtained and the methodological theory which influenced the design of each study. Although subjects are described in the body of each research report this chapter assembles information about all of the subjects into appendices. This facilitates visualization of the people investigated as a group and clarifies which staff and clients were present in more than one study. Patterns of participation were dictated by the nature of each study but were also influenced by changes in the staff and clients of participating units, and clients becoming ill or recovering from previous illnesses. Appendix A states which subjects took part in each study and allocates them a number which remains theirs throughout these reports. Information about staff was not taken. Nearly all of the staff who took part had neither health nor social services qualifications: the three who did would be instantly identifiable if that were to be reported.

Appendix B gives a summary of the clients' abilities on the Schedule of Growing Skills, alongside which unit they were observed in and what type of residence they lived in. Appendix C describes their known disabilities and gives a brief pen portrait of them. Appendix D describes the behaviour of every client except those who were in the pilot study alone. These behaviours were allocated to one of three major behaviour codes which were derived from observation and from the literature. The development of the coding scheme is described in chapter 6.

The first section of this chapter covers the development of the sample, estimates the size of the population of profoundly intellectually disabled adults as a whole and considers the relationship between the two. The second section considers design issues as they relate to the investigations which were undertaken.

5.1 INFORMATION ABOUT THE SAMPLE AS A WHOLE.

Adults with profound intellectual disability are a numerically small group whose multiple needs and heterogeneity present challenges to researchers. Prevalence rates are commonly combined with people who are severely intellectually disabled (for review, see Fryers, 1984, or Hogg & Sebba, 1986). Across children and adults, Eyman & Miller (1978) suggest a prevalence rate of 0.5 per 1000 for profoundly intellectually disabled people.

The group are difficult to identify. Classification of levels of intellectual disability have depended upon IQ scores, people scoring below 20 or 25 being classified as profoundly disabled (Grossman, 1983). However, most surveys of profoundly disabled people do not use IQ scores. Some have relied on placement criteria, surveying everyone who attends a special care facility. Other researchers list which lack of functional abilities would qualify an individual for inclusion in their study. A third approach has been to follow Hogg, Foxen & McBrien (1981) who define a profoundly intellectually disabled child as one whose score on a developmental assessment is less than or equal to one quarter of their chronological age. In their survey of children and adults with profound disability Hogg et al (1988) included adults who had a developmental age of 3 years or less.

The catchment population of the health district concerned was 612,000. Eyman & Miller's (1978) prevalence rate predicts that 306 children and adults with profound disability live in the area but it is difficult to derive a figure for adults alone from this information. Another approach is to look at facilities provided for people with profound disability. There were 6 day and residential units managed by health and social services for such individuals at that time, providing a total of 120 places (this includes a reduction for some overlap between the two types of facilities). A few people who present challenging behaviour but are not profoundly disabled are placed in social services special care units and so this figure might be reduced to 110. This is the estimated number of adults with profound intellectual disability in the catchment area.

A total of 26 people took part in one or more parts of this investigation, approximately one quarter of the estimated population. No comment can be made about their representativeness apart from that they were drawn from both health and social services populations. Subjects were drawn from one, two or three different units for people with profound disability, according to the needs of each study.

5.2 METHODOLOGICAL CONSIDERATION OF INTERACTIONS WITH PROFOUNDLY INTELLECTUALLY DISABLED ADULTS.

Some methodological issues were discussed in chapter 1, including changes in acceptable and relevant modes of investigation. Two design points were emphasised: the importance of viewing participants as people with their own assumptions and contribution to make, and the importance of considering whether the project design or the results could be used against the interests of the participants. Studies of interactions between staff and profoundly disabled clients have generally observed from a distance and reported those observations apparently without discussion. There is no information from the staff about any difficulties they experience in trying to work with such clients nor how they interpreted the clients' behaviour.

The present investigations of interaction were carried out with, rather than on, staff. Results of such a study are likely either to demonstrate the difficulties of interacting with profoundly disabled people or to provide information about successful strategies which inexperienced or struggling staff could use. The implications of either of these outcomes for staff seem preferable to the current research findings which catalogue brief and infrequent contacts.

With regard to the clients themselves, it seemed likely that they would benefit from increased social contact with their keyworker during an investigation of interaction. If the keyworker felt they had gained confidence or some new insight there was also a chance that they would put it into practice to the benefit of the client. The other advantage of research with keyworkers is that they continue to be in contact with the clients after the project ends.

This section of chapter 5 discusses interactional analysis in three sub-sections. The first concerns setting and design issues; the second concerns the derivation of coding schemes and data analysis; the third discusses issues of reliability.

5.2.1: SETTING AND DESIGN ISSUES.

There are now many psychologists who recommend studying people in natural, informal settings rather than asking them to interact in strange laboratory settings. This is the position advocated by researchers using qualitative techniques (for example, Marshall & Rossman 1989) who believe that since people respond to their settings the artificial culture of a laboratory must have an influence on results. This is an argument also used by developmental psychologists such as Dunn (1982) who recommended as a model a study of sibling responsiveness carried out in the home by a single researcher using a cassette recorder. However, there are a number of laboratory-based research studies which used two video cameras to combine the faces of both interactants onto a split screen (for example the work reported above by Als, 1982) which would not have produced such detailed and useful information without complicated equipment.

The other major design issue in observational research is the degree to which, if at all, the experimenter directly sets out to influence the behaviour of one or both interactants. This is not generally done in qualitative research nor in quantitative observational research(for example, Bakeman & Gottman, 1986), both of which usually concentrate on naturally-occurring events. However, such influence can occur within a 'quasi-experimental' framework if the research question is concerned with predicting the outcomes of various phenomena (see table3.3, p78, Marshall & Rossman 1989). This approach, also referred to as 'quasi-ethological' (Griffiths, 1989), has been used to identify the direction of effects among correlational data obtained from observation (Wood & Wood, 1984).

5.3.2: THE DERIVATION OF CODING SCHEMES AND DATA ANALYSIS.

Bakeman & Gottman (1986) suggest that exploratory research can be useful but that some conceptualisation needs to occur at the early stages if psychologists are to avoid being overwhelmed by their data. Their advice is that borrowing someone else's coding scheme is like borrowing their underwear: they see a coding scheme as the lens through which the researcher views the particular behaviour under investigation.

This is not a universally held view. Landesman-Ramey et al (1989) recently criticised the range of different schemes used to describe family functioning suggesting that this leads to an accumulation of piecemeal data which does not create a coherent body of knowledge. However, their hope that a single scheme can be agreed has not occurred so far in observational research with primates or with babies. Sackett (1978) described failed attempts to agree such a scheme, suggesting that constant changes in measurement conditions and research goals meant that a single coding scheme would never meet the needs of all the investigators studying a particular problem.

Bakeman and Gottman (1986) suggest that one way to decide which behaviours are important is to make some observations and write a narrative description from them. From this the coding scheme can be drawn up and refined until the behaviours coded are mutually exclusive and exhaustive, the behaviours are at the same level of analysis and the scheme can be used reliably by trained observers. This was done with the pilot study interactions from which the coding scheme used in the following three studies was derived by combining the narrative with the theoretical conceptualization of the issues described in chapter 4. The role of the keyworkers in interpreting the behaviour of their client is described in chapter 6. Records of the way that each client's behaviour was interpreted are in appendix D.

Qualitative researchers (Marshall & Rossman, 1989) also describe a process for reaching agreement about aspects of behaviour but their level of analysis and criteria of acceptable reliability are different. The credibility of these classifications is checked by debate with other researchers playing devil's advocate, trying to propose alternative ways of viewing the information collected, negotiating changes in the classification system or narrative description which is to form part of the data. Thus the qualitative researchers may end with a negotiated narrative description which was the starting-point for the observational research team. Both quantitative and qualitative analyses were carried out in the last study of this set, reported in chapter 9.

Sequential observational research has been characterised as scientific whereas narrative description is humanistic. With systematic observation the derivation of a coding scheme and the training of observers yields information which can be analyzed quantitatively. Sackett (1978) noted that very little observational data was reported about intellectually disabled people and that where it did exist it had been gathered to solve a specific problem. He hoped that quantitative observational data could enlarge the descriptive base of facts about disabled people and facilitate hypothesis-testing about the nature of disability. He wrote : "I believed that these views might provide a focus for designing experiments to describe and understand the variations in behavioral adaptation used by retarded people living under various ecological-social conditions."pxii.

Nearly ten years later Bakeman & Gottman (1986) stated that observational research allows psychologists to investigate areas of behaviour "previously recalcitrant to quantitative analysis..." (p201). They argued that the most recent contribution was to think about interaction in terms of its temporal patterns and repetitions, and that considering issues from this perspective would result in increased conceptual clarity.

Data may be analysed using standard behavioural statistics (for example, Guilford & Fruchter, 1981; Siegel & Castellan, 1988) or by some of the specialised techniques which have been developed to suit observational data (for example, Lemon & Chatfield 1971; Sackett, 1978; Cairns, 1979; Sackett,1979 and Bakeman & Gottman, 1986). This set of references also contain details of the design of interactional research. Lemon & Chatfield describe the computation of transitional probabilities when transitions from one behaviour to the same behaviour are excluded. Sackett (1978) and Cairns (1979) provide edited sets of papers describing techniques for coding, recording, and analysing observational data. Sackett (1979) describes the lag sequential analysis of data so that patterns of behaviour may be identified. Some of these techniques were applied in the quantitative analysis of data from the last study reported in chapter 9.

5.3.3 RELIABILITY AND VALIDITY ISSUES.

As was indicated in the previous chapter one of the tenets of observational research, according to Bakeman & Gottman (1986), is that data are checked by more than one observer and interobserver agreements are computed and provided. In observational research reliability has been debated in great detail while relatively little attention has been paid to validity. There has been a recognition of the difficulty of obtaining any criteria of 'truth' other than that two or more people independently agree that the same event has occurred; it has often been assumed that if inter-observer reliability can be demonstrated the results have some measure of validity (for example, by Bakeman & Gottman, 1986).

Hollenbeck (1978) described problems of reliability in observational research in two areas, those associated with the person making the observations and difficulty in identifying a statistical measure of inter-observer agreement. Problems associated with the person making the observations concern a variety of possible effects of the observer upon the situation being studied and also the assessment circumstances in which observers code behaviours. Observer effects on situations which have been identified include why subjects think the study is being done, the conspicuousness of the observer and equipment, and also that some subjects seem to react strongly while others are apparently unaffected. Factors influencing coders include initial training, whether their accuracy is overtly or covertly checked and the length of time the observers are involved with the study, more than a month or two being associated with observer drift or decay.

Problems associated with statistical treatment of inter-observer agreement is a more complex topic. Hollenbeck (1978) and Bakeman & Gottman (1986) emphasise that this is merely a measure of agreement and not a measure of reliability unless the results can be compared to a standard. In observational research this is very rarely the case. Both Hollenbeck and Bakeman & Gottman conclude that Cohen's Kappa is the statistic of choice as it corrects for the element of chance associated with the number of categories in a coding system. Criteria for evaluating values of Kappa vary: Landis & Koch (1977) suggested that agreement from 0 to 0.2 was 'slight', from 0.21 to 0.4 was 'fair', that 0.41 to 0.6 was moderate, from 0.61 to 0.8 was 'substantial' and from 0.81 to 1.00 was almost perfect. Bakeman & Gottman (1986) state "Our own inclination...is to regard Kappas less than .7 ... with some concern, but this is only an informal rule of thumb."(p82).

Uebersax (1988) has recently described a number of difficulties with Kappa, questioning whether it was reasonable to assume that guessing affects the rating process to any degree at all. Uebersax suggested that a rater may be misled about someone by a piece of information or the rater's use of decision rules may be inaccurate but that these were not the same as making ratings by chance. In reporting inter- and intra- rater agreements for the following studies both agreement percentages and Cohen's Kappa are given.

People arguing for qualitative research approach reliability differently: the following quotation from Marshall & Rossman (1989) illustrates their position. "Positivist notions of reliability assume an unchanging universe, where enquiry could, quite logically, be replicated. This assumption of an unchanging social world is in direct contrast to the qualitative/interpretive assumption that the social world is always changing and the concept of replication is itself problematic."(p147).

Marshall and Rossman(1989) seem less clear about the role of validity. Initially they state that internal and external validity are also inappropriate constructs for qualitative enquiry using instead the term 'credibility'. However, in the following paragraph they describe the strength of qualitative study as being in its validity, saying : "An in-depth description showing the complexities of variables and interactions will be so embedded with data derived from the setting that it cannot help but be valid."(p145). While it may be difficult to understand their view of good research design their argument against traditional approaches is clear: academic psychological study loses important, holistic information about people in its search for reliability and scientific respectability. This view was also promulgated in Reason & Rowan's (1981) book, and it led to the decision to carry out a qualitative analysis of the final investigation as well as a quantitative one.

SUMMARY OF SECTION 5.3

This section examined key methodological issues in interactional research. These are consideration of the setting and process of collecting observational data combined with derivation of coding schemes. The benefits of sequential analysis of observational data were discussed alongside the difficulties of ensuring reliability and validity.

This information was counterpointed by the views of qualitative researchers. Landesman-Ramey et al (1989) recently recommended analyzing interactions both quantitatively and qualitatively rather than viewing these techniques antagonistically. This may be particularly useful in the case of profoundly intellectually disabled adults as knowledge of neither their nature nor of ways to interact with them exist in any depth.

CHAPTER 6: THE PILOT STUDY INTO INTERACTIONS BETWEEN STAFF AND PROFOUNDLY INTELLECTUALLY DISABLED ADULTS

AIMS

1. To investigate staff-client interactions under the most favourable conditions.

2. To discover whether a single behavioural coding scheme could be drawn up which included all possible responses from clients with different types of disabilities.

3. To determine the appropriate length of sessions for examining staff-client interactions.

4. To describe the interactive strategies which staff were using with clients.

METHOD

SUBJECTS

Clients were identified as profoundly disabled if they had a developmental age of 3 years or less on the Schedule of Growing Skills (Bellman & Cash, 1987). Staff who had worked with one of these clients for 3 months or more were then approached. Staff heard about the project and saw themselves on videotape, singly or in pairs, before being asked to consent. They were reassured that the tapes of them interacting with their client would only be seen by themselves and by people on the research team.

Simultaneously, next of kin of the clients were approached by a letter which explained the project and requested that they sign a consent form agreeing that their relative take part.

The people who took part were pairs where both the next of kin of a client and the staff member keyworking with that client consented. As this was a pilot study it was decided to include in addition the most experienced staff member. This person managed the unit and did not keywork with any particular client and so one of the participating clients worked with two staff members, his keyworker and the unit head. The pairs who took part in the pilot study are in Appendix A as pairs 1,2,3,4,5,9,18,21 and 22: pairs 4 and 9 include the same client but different staff. Appendix A lists their participation in all stages of this research; the abilities of the clients on the Schedule of Growing Skills are summarised in Appendix B and their characteristics and disabilities are described in Appendix C.

The client group

N=8.

AGE: range=23-39 years, median age=30 years.

Developmental ages (expressed as the median of their attainments on the Schedule of Growing Skills)
Range: 1-12 months, median=6.75 months.

Non-ambulant = 5
Blind=2
No additional disabilities =1

The staff group

All had known their client for at least 3 months. One had an RNMH qualification in nursing, two had SEN qualifications, the others held no nursing qualifications. They worked in an NHS residential unit for people with profound developmental disability containing 20 permanent residents, which included the eight described here.

PROCEDURE

Interactive sessions were recorded by the experimenter filming the two people on a portable video camera. Filming took place at times which staff felt were appropriate to the clients' needs and on days when they seemed well. If the client was ill, agitated or asleep when a session was scheduled it was postponed.

Filming was carried out in the client's bedroom with only the keyworker and the experimenter present. Prior to the session staff were asked to think about how they might spend time with a client when they had some spare moments. The sessions were not necessarily about teaching the client anything, they were designed to find out how staff usually spent time with the person. Staff were encouraged to do anything which was in their normal routine and to try to engage the person in more than one way during the session if they wished. They were asked to avoid eating and drinking. The aim of the investigation was restated before the session as an investigation of how staff make and maintain relationships with profoundly disabled adults. Sessions were 10 minutes long. Staff viewed the sessions afterwards and any comments they made were noted.

RESULTS

Sessions were analysed qualitatively by the author, who made a narrative account of the main features of each session. From these accounts the following points emerged.

1. Client behaviour coding scheme.

The different disabilities and behaviours of each client made it impossible to draw up a coding scheme which included all behaviours and was mutually exclusive and exhaustive. Not only did the behavioural repertoire vary from client to client, the same behaviour was also interpreted differently between clients. For example, one client's head-weaving was described as a stereotyped behaviour while another's was considered to indicate pleasure and happiness.

It was possible to assign different behaviours to a general coding scheme which described four types of behaviour: those indicating positive affect, those indicating negative affect, behaviours which were stereotyped, and behaviour which indicated neutrality or passivity. These categories included the following types of behaviours.

Positive:
This could include responses which were social - looking, smiling at someone, reaching towards or touching someone- but it could also include behaviours which indicated contentment but did not necessarily have a social component - humming or rocking could be examples.

Negative:
This included behaviours which seemed to be rejecting social

contact - turning away, walking off, hands over ears - as well as behaviours which suggested the person's affective state was negative - scowling, screaming, self-injury.

Stereotyped behaviours:
This included behaviours which had a repetitive component but which were not understood to indicate a positive or a negative state. Self-injurious behaviours were not included here but in the negative category. Involuntary reflexive behaviours were classified under this heading.

Neutral:
All behaviours which seemed to show that the person was alert but not responding actively.

Uncodable:
This was for behaviours which could not be interpreted into any of the above four categories and for those pieces of film where interpretation was hampered by technical difficulties.

The last category ensures that the coding scheme is exhaustive, that is it can include all possible behaviours.

1. Length of sessions.

Two types of information provided the basis for deciding the length of future interaction sessions.

a) Time when the session ended.
Pair 1 - client walked off for first time at 3 min 30 sec; walked off again at 7 min 30 sec (filming continued as client led staff around the house). Client finished the session by walking into the lounge at 9 min.

Pair 2 - session ended at 4 min 30 sec as client becoming agitated.
Pair 3 - 3 min 40 sec client lay down on the bed and refused to continue.
Pair 4 - session ended at 5 minutes, but staff had first signalled difficulty at 50 seconds by looking at the camera and pulling faces and did so intermittently until the client brought the session to an end.
Pair 5 -client ended session by walking off at 6 min 20 sec.
Pair 9 -the only pair to complete 10 minutes (staff member afterwards said it felt much too long).
Pair 18 -session ended at 9 min.
Pair 21 -session ended by staff at 9 min but there had been pauses and requests to stop at 2 min 40, 4 min 40, 7 min and 8 min. Between these pauses the level of animation suggested it was reasonable to continue for a while.
Pair 22 - session ended by experimenter at 8 min 40 as the staff member was repeating a limited number of approaches with no new behaviour on either side.

b) time beyond which no new behaviour was observed from either party
Pair 1 - 3 min 30 sec.
Pair 2 - 3 min 20 sec.
Pair 3 - 3 min 2 sec.
Pair 4 - 1 min
Pair 5 - 5 min 40 sec.
Pair 9 - 4 min 25 sec.
Pair 18 - 6 min 40 sec.
Pair 21 - 2 min 40 sec.
Pair 22 - 5 min 30 sec.

Group mean - 3 min 58 sec.

3. Staff strategies observed.

a) Talking.

All staff talked with their client at some point.

b) Choice-offering.

Pair 1-staff offered different musical instruments.

Pair 2 - staff offered choice between mirror and music box, later offered rattle or mirror.

Pair 4 - asked if wants to stay in or go outside.

c) Instruction.

Pair 1 - shows client how to use tambourine.

Pair 2 - shows client how to make jack-in-the-box work by putting his hand on the button.

Pair 4 - shows client how to co-operate with gloves being put on.

Pair 5 - tells client to hold head up and uses physical prompts.

Pair 22 -shows client how to clap by physical guidance.

d) Responding contingent on the client's behaviour.

Pair 1 - client ended one activity and lay down inviting a familiar game, staff responded.

Pair 9 - client smiles, staff smiles. Client's chest wheezes, staff comments on it. Client claps hands, staff comments. Client reaches to staff, staff asks if he wants to stand.

Pair 21 - client coughs, staff responds with sympathy. Client makes noises which staff imitates.

Pair 22 - client makes sounds which staff imitates.

e) Social routines.

Pair 1 - the aeroplane game. This client watched as the staff held a hand high in the airand made zooming noises while increasing the excitement using voice and face and naming the client. The hand loomed toward the client until it ended in tickling him. The client laughed and then requested repetition by holding the staff's hand up again.

Pair 9 - Staff offered assistance to stand in a number of stages. This seemed to be a known sequence ending in supported standing, a source of pleasure for this physically disabled man.

Pair 18 - staff danced before the client, involving her by calling her name softly; once attention was gained staff danced up towards her, singing increasingly loudly and with more facial animation until the client's hand was held and jogged in time to the music. Staff then retreated and repeated the sequence.

Pair 21 - staff called client's name with increasing animation and brought her face increasingly close until he laughed. This was sometimes ended by the staff tickling the client.

Pair 22 - staff stimulated the client with 'round and round the garden' accompanied by increasing animation in face and voice and ending in tickling.

DISCUSSION

This study was designed to investigate staff-client interactions at times when the client was alert and well and the member of staff had no competing demands on their attention. Filming in natural surroundings but doing so at times and in places which had been set aside seemed to be a useful technique.

The coding scheme was devised to allow for individual variation and also to facilitate comparison across people with different disabilities. The classification of behaviour into positive, negative, stereotyped and neutral behaviour is much simpler than those described by Brazelton (1973) or Als(1982). Since this approach was going to require interpretation of each individual's behaviour by staff who were unaccustomed to developmental research it was felt that using complex categories such as 'monitoring' could make the task too difficult. It was more likely that people would be able to interpret behaviours as generally indicating pleasure, displeasure or a neutral response. The frequent occurrence of stereotyped behaviours and their unique nature suggested that these should be included as a separate category. As this was an exploratory research project clients' behaviour was coded into these four broad categories: analysis at this level was more likely to identify issues for further investigation.

This coding scheme could be construed as being on a continuum of arousal or state concerning the focus of an individual's attention. Positive behaviours could be assumed to be outer-directed and communicative in nature, neutral behaviours could represent a transitional or intermediate state while stereotyped behaviours could be understood as being inner-directed since individuals are less responsive to environmental stimuli when engaged in stereotypy. Negative behaviours were defined to include self-injurious responses and behaviours rejecting the keyworker. Negative behaviours could therefore also be seen to indicate a preference for being left in an inner-directed state. Precisely how the literature on arousal in babies can be applied to 'state' or alertness in intellectually disabled adults remains to be elucidated, although Sternberg & Richards' (1989) article has opened the debate.

The keyworker's interpretation of the meaning of each behaviour displayed by their client is central to this scheme. They were to be asked into which of the four categories each of their client's behaviours should be put. This would be done in future experiments by showing the videotape of the keyworker interacting with the client to the keyworker. When two behaviours occur simultaneously, for example the client looking at the keyworker while making stereotyped movements, the keyworker would be asked to say whether they had felt at that moment that the person was paying attention mainly to them and the stereotypy was secondary or vice versa.

Determining the length of sessions for future studies was done by combining research information with the results obtained here. Moores & Grant (1976) had found that most interactions took less than 30 seconds and that only a very small percentage lasted as long as three minutes, although their study was carried out in a different environment from the current one. The results of this study found that no new behaviour was observed from either keyworker or client after about 4 minutes, on average. However, one third of this staff group had signalled a wish to end sessions sooner than that and so the length of future sessions was set at 3 minutes.

Each of the strategies used by staff when interacting with their client can be linked to themes in the research literature. Staff talking with clients could be interpreted within Bruner's (1975) framework, showing that staff assume the client has understanding and that they are treating the individual as a fellow human being. Wood & Wood's (1984) analysis of communication between teachers and deaf children gives another perspective on this. They found that children were most likely to speak in response to a personal contribution. It is possible that talking about events with a profoundly disabled person facilitates a social response in a similar manner even if this is non-verbal. The last perspective on talking as a strategy comes from Kelly's Personal Construct Theory (1955), which emphasised the importance of interaction between people so that they can start to predict one another's behaviour. Talking may be useful because it provides a way for staff to stay in contact long enough for the client to be able to predict their behaviour.

Offering choice is a topic which Glenn & Cunningham (1984) demonstrated to be meaningful for some profoundly disabled children by use of equipment which allowed the children to express their choices. It is also a theme which has been discussed by Wolfensberger (1972; 1983) as an important step towards helping clients to control their own lives. However, if keyworkers offer choice by providing alternatives and asking the client to choose this becomes a strategy closer to that used by some teachers described by Wood & Wood (1984). When teachers asked deaf children a closed question they were unlikely to obtain much speech. The authors argue that closed questions are conversational moves which place the teacher in control of the dialogue and that strategies which are less controlling are more likely to facilitate speaking in deaf children. Profoundly disabled clients may find it equally difficult to respond to keyworker's requests for them to decide between two options.

Instructing clients in a session which was held to investigate interaction has no clear links with the theoretical literature. It suggests that an educational approach dominates services for disabled people. One possible explanation from the research literature could be the results showing that parents and staff are more likely to use directive language in interaction with disabled people (Berger & Cunningham,1983; Mahoney, 1988). Perhaps the preference for an instructional approach shown by some members of staff is an extension of that finding.

Responding in a client-centred way has been recommended by a number of psychologists (Wood & Wood, 1984; Mahoney, 1988; Wootton, 1989). It was observed here in a variety of guises, all of them apparently giving value to whatever the client did. Responding contingently may be understood as an example of Buber's (1958) I-Thou relation, since one characteristic of this is that the "I" allows the other to come forward to meet them. Providing acknowledgement of the profoundly disabled person's behaviour may be one way to create mutuality within a relatively unequal relationship.

The final strategy observed was the use of established social routines. These involved engaging the client's attention and increasing arousal by use of face, voice and changes of pace which ended in tickling and laughter. Variations on this theme were that the increase in alertness led to the client being involved in a dance or that the client was engaged in a sequence which ended in supported standing. These social routines seemed to be meaningful to clients because they facilitated their anticipation of events.

Social routines in interaction have been described by a number of psychologists. Sroufe's (1979) theory proposes that tension - physiological arousal combined with expectation - is necessary for smiling and laughter and is a key component of socio-emotional development. Bruner (1975) described the importance of formats in linguistic exchanges between infants and parents. He suggested that the repetition of social exchanges helps the infant to understand when it is their turn and how they may fill it. Kelly's (1955) emphasis on predictability in human relationships is also relevant here.

CONCLUSIONS

This pilot study showed that staff-client interactions can be investigated using a quasi-ethological technique and that staff were willing to volunteer to work with such a project. The pilot study found that 10 minute sessions yielded no new information after an average of 4 minutes and that some staff-client pairs preferred shorter periods of interaction. The length of future sessions was set at 3 minutes.

The pilot study suggested that a single coding scheme could not describe the range of behaviours observed in profoundly developmentally disabled adults but that individual schemes could be drawn up which described every client's repertoire under the same four categories; positive, negative, stereotyped and neutral. Such a coding scheme involves the keyworker in interpreting each of the client's behaviours and judging which one dominates when two occur simultaneously.

A wealth of different strategies were used by staff when interacting with their client. These were described under five general headings; Talk, Choice, Instruction, Contingent Responding and Social Routines. Each strategy observed in the interactions could be interpreted in relation to the research literature.

CHAPTER 7: THE ANALYSIS OF PROFOUNDLY INTELLECTUALLY DISABLED CLIENTS' RESPONSES TO DIFFERENT STAFF INTERACTION STRATEGIES

This study systematically varied the staff strategies identified in the pilot study so that their effects on client responses could be determined, using an own-control design. It was carried out with staff-client pairs from an NHS residential unit and a social services day center.

AIMS

1. To investigate whether staff can systematically vary the social interaction strategies they use with profoundly disabled clients.

2. To investigate whether the behavioural coding scheme drawn up in the pilot study can be used reliably by the same observer and by two different observers.

3. To investigate whether the staff strategies Talk, Choice, Instruct, Contingent Responding and Social Routines (described in the previous chapter) have an effect upon the amount of positive, negative, stereotyped or neutral responding shown by clients. These effects will be examined against baseline responding and also against each other.

METHOD

EQUIPMENT

All sessions were recorded on videotape and analysed using a player which allowed examination of the sessions at normal speed, at one tenth of a second and held on pause. A clock was added to the picture to facilitate analysis. This equipment did not provide sound at slow speeds and so analysis of vocalisations was not carried out.

SUBJECTS

Subjects were sought from two units for adults with profound intellectual disability. Unit A was the NHS residential unit which took part in the pilot study. Unit B was a social services special care unit within a day centre. Consent was sought from both the staff and the next of kin of clients in the same way as was described in chapter 6.

In unit A the next of kin of 10 clients were contacted and the 10 keyworking members of staff were invited to consider the project. All of the staff consented but only 5 staff-client pairs took part, either due to illness in the client or because consent was not obtained from next of kin. In this unit staff elected to act as keyworker for particular clients. In unit B, 4 of the 9 members of staff agreed to take part. Profoundly disabled clients in the key groups of these volunteers were identified and letters requesting consent from next of kin sent out. Staff selected the person they were most interested in working with from those for whom consent had been obtained.

The nine staff-client pairs who took part in this investigation are listed in Appendix A as 5,6,7,8,18,21,22,26,28. Details of the clients' abilities on the Schedule of Growing Skills are given in Appendix B; details of the clients' disabilities and a portrait of their characteristics are given in Appendix C; details of the behavioural classification for the coding scheme are given in Appendix D. The following information summarises these individual details.

The client group

N=9

AGE: range=17-34 years, median age=25 years.

Developmental ages (expressed as the median of their attainments on the Schedule of Growing Skills):
range=1-9 months, median=4.5 months.

Additional disabilities:
Blind/partially sighted 3
Hearing impaired 1
Unable to move body through space 4
Non-ambulant but moves by shuffling or crawling 2

All clients had at least one additional disability.

Self-injury:
4 people injured their faces by hitting or slapping, 2 doing so severely enough to have their arms restrained in gaiters when unattended.

The staff group

All had known the client for at least 3 months. Two members of staff held relevant qualifications, one in nursing one in social work, while the remaining seven did not.

DESIGN

This investigation used an own-control design where subjects' behaviour under baseline conditions was compared with their behaviour under each of five intervention conditions. The interventions, described below under independent variables, were applied in random order for each staff-client pair.

1. The dependent variables

For each client a set of behaviours were agreed by the experimenter and the keyworker as indicating positive, negative or stereotyped behaviours (previously described in chapter 6). Absence of these behaviours in a client who remains alert was coded as neutral while any other event went into the uncodable category. These behavioural descriptions were negotiated while looking at films of the client. It was explained to the keyworker that a difference of opinion between the experimenter's and their interpretation was possible and that their view would be recorded in that event, although it did not occur in this investigation.

2. The independent variables

These were the interactive strategies used by staff which were identified in the pilot study. As not all of the staff were familiar with all of the strategies they were explained as follows.

TALK. Staff were asked to talk to the client in a natural and undemanding manner, perhaps describing a joint activity or telling the client of a holiday. It was suggested that they had two or three different topics in mind before the start of the session.

CHOICE. Staff were asked to present the client with two or three different choices during the course of a session. These choices were to be between two items presented in a manner which requested that the client indicate which they preferred. No more than one of the discriminations should concern food or drink and this should be the last so that consuming the chosen item did not use up the session time.

INSTRUCTION. As both units aimed to help clients to develop new skills such interactions were familiar to staff. They were asked to select a task which they felt was relevant to the client's needs and the sort of skill they would plan or were perhaps already teaching them. Tasks which could be done within the 3 minute session were preferred.

CONTINGENT RESPONDING. Staff were asked not to initiate contact with the client but to follow their lead. They were told to communicate to the client that they were interested in anything the client did. Examples of appropriate responding under this condition were imitating a vocalisation, commenting on something the client looked at and looking in the same direction or patting them on the back if they coughed. Having made their response staff were asked not to do anything which would continue the interaction, returning to their watchful position ready to respond to the next behaviour from the client.

SOCIAL ROUTINES. Staff were asked to build up a repeating behavioural pattern with their client if such a social routine did not exist between them. Most of the pre-existing routines were tickling games. New routines should involve a sequence of three or four steps which ended in something that the client was known to like. The key point was to repeat the sequence so that the client could start to predict that the pleasurable event was imminent, so each sequence should last about a minute and be repeated three times in the session.

3. Validity.

This was checked by a rater naive to the purpose of the study. She was given a written description of each of the interactive strategies listed above and asked to view the sessions in the random order in which they had been filmed. The rater recorded which interactive strategy the staff member seemed to be using in each session and gave a confidence rating for the judgement.

4. Reliability.

All sessions were coded by the experimenter, following the coding criteria agreed with the keyworker and described in Appendix D. Inter-rater reliability was assessed by the above naive rater being asked to code the sessions of the 3 clients who had seemed the most difficult to code. The rater was given the coding scheme and trained in the use of the recording sheets, clock and videoequipment but not trained on the interpretation of the behavioural categories themselves. It was considered useful to have an external check on the use of schemes which involved subjective social judgements.

Intra-rater reliability was assessed by the experimenter re-scoring the sessions for another 3 clients at least one month after the first analysis. These clients were selected by a third party who nominated them from the 6 who were not in the inter-rater reliability check.

PROCEDURE

Each staff member was asked to interact with their client for 3 minutes in any way they wished, using any equipment they wished and positioning the client however they felt appropriate.

Instructions were the same as for the pilot study, as were filming conditions - in the person's bedroom on the residential unit or in a quiet room known to the clients in the day centre. As this was to form the baseline measure for the rest of the study staff were asked afterwards if they felt their own or the client's behaviour was unusual: if so the session was re-filmed on another occasion.

Following this baseline session staff were given a list of the order in which they would do each of the five interaction strategies, the order having been randomized for each pair. The content of the next session was discussed with them at the end of the previous session so that they had time to think about what would be most appropriate for their client. Further discussion was held between the experimenter and the staff member before each interactive session so that the content could be negotiated. Staff described what they were thinking of doing, why they thought this was most appropriate for their client and meaningful for themselves. Suggestions were made if staff were not sure how to proceed. They were given the opportunity to try out an interaction strategy with their client before the session was filmed if this was helpful. Staff were given the power of veto over the session after filming if the client had seemed ill: this was rarely used as normally an ill or sleepy client was observed before filming and the session postponed.

All sessions lasted for 3 minutes. Sessions were filmed separately, no closer than one in the morning and the other in the afternoon. The baseline and five interaction strategies were filmed within three weeks for any staff-client pair.

RESULTS

The following questions were asked of the data.

1. Did staff change their interaction strategy between sessions?

2. Is the coding reliable?
3. Under what conditions do clients show more positive behaviour?
4. Under what conditions do clients show more negative behaviour?
5. Under what conditions do clients show more stereotyped behaviour?
6. Under what conditions do clients show more neutral behaviour?
7. What individual differences are there where clients behave differently?

1. Did staff change their interaction strategy between sessions?

The rater who watched the randomized tapes correctly assigned all of the sessions to the strategies which staff had been asked to follow. The rater was 'sure' of the strategy on 89% sessions, 'fairly sure' on 4% and 'doubtful' on 7%.

2. Is the coding reliable?

For both the original coding and the re-check, data on how many seconds clients spent in each behaviour type was summed into each of the 5 categories and the set of 6 sessions compiled into one. These total figures were compared with the second ratings by entering total agreements into the diagonals of the matrix and allocating disagreements to cells through inspection of the record sheets. The level of agreement was assessed using Cohen's Kappa (see Bakeman & Gottman, 1986) and the strength of agreement of Kappa described using Landis & Koch's (1977) categories[1].

a)Intra-rater agreement.

The baseline and five interaction sessions were re-scored by the

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[1] Landis & Koch's categories are as follows: 0-0.2, slight; 0.21-0.4, fair; 0.41-0.6, moderate; 0.61-0.8, substantial; 0.81-1.00, almost perfect.

experimenter for 3 clients.

Client	% Agree.	Kappa	Kappa agreement
5	93%	0.83	Almost perfect
7	93%	0.86	Almost perfect
26	92%	0.85	Almost perfect

b) Inter-rater agreement.

The three clients whom the experimenter had found most difficult to code were checked by a naive rater using the same techniques.

Client	% Agree.	Kappa	Agreement
18	72%	0.46	Moderate
21	86%	0.73	Substantial
28	62%	0.38	Fair

3. Under what conditions do clients show more positive behaviour?

Table 3.1 The time in seconds of positive behaviour made by each client during each strategy.

Client	Base.	Talk	Ch.	Inst.	C.R.	Soc.R.
5	53	83	10	6	35	59
6	30	76	5	21	-	143
7	114	154	99	26	12	120
8	15	19	51	46	34	130
18	142	163	109	14	9	106
21	69	91	10	44	2	78
22	94	125	-	6	45	123
26	10	92	20	24	154	148
28	5	50	-	2	-	112
med	53	91	10	21	12	120

Results were analysed using the Wilcoxon matched pairs signed ranks test. A two-tailed test of significance was used as there was no previous research to predict effects in either direction. Results were analysed following the procedure described by Siegel & Castellan (1988) and the significance of T values is taken from there.

The Talk strategy produced significantly more positive behaviour than Baseline (p<.01), than Choice (p<.01), than Instruct (p<.01) and than Contingent Responding (p<.05).

The Social Routines strategy produced significantly more positive behaviour than Baseline (p<.05), than Choice (p<.05), than Instruct (p<.01) and than Contingent Responding (p<.01).

4. Under what conditions do clients show more negative behaviour?

Table 4.1: The time in seconds of negative behaviour made by each client during each strategy.

Client	Base.	Talk	Ch.	Inst.	C.R.	S.R.
5	8	-	5	26	5	1
6	3	-	-	4	3	14
7	-	-	-	-	-	-
8	-	-	-	-	-	-
18	-	-	-	-	-	-
21	22	-	12	-	-	-
22	1	-	10	5	-	-
26	5	-	40	-	-	-
28	4	-	-	51	-	1

As 3 people never showed negative behaviour the figures were too small for analysis. However, it is interesting to note that Talk was the only strategy in which no client behaved negatively.

5. Under what conditions do clients show more stereotyped behaviour?

Table 5.1: The time in seconds of stereotyped behaviour shown by each client during each strategy.

Client	Base.	Talk	Ch.	Inst.	C.R.	S.R
5	-	-	-	-	-	-
6	4	22	-	6	131	-
7	-	-	-	-	-	-
8	-	-	-	-	-	-
18	1	-	-	-	86	17
21	-	-	-	-	-	-
22	58	-	95	12	97	-
26	-	-	-	-	-	-
28	-	-	-	-	-	-

Only 3 of the subjects showed stereotyped behaviour under any condition, too few for analysis. However, those three showed a notable increase in stereotyped behaviour under Contingent Responding.

6. Under what conditions do clients show more neutral behaviour?

Table 6.1: The time in seconds of neutral behaviour shown by each client during each strategy.

Client	Base.	Talk	Ch.	Inst.	C.R.	S.R.
5	113	91	159	141	127	116
6	67	76	152	148	43	24
7	62	23	77	142	163	56
8	159	160	125	130	141	36
18	32	12	66	152	81	51
21	81	83	151	120	171	82
22	20	48	70	152	32	49
26	154	84	113	151	22	28
28	165	126	175	123	175	59
med.	81	83	125	142	127	51

Talk produced significantly less neutral behaviour than Choice ($p<.05$) and than Instruct ($p<.05$).

Social Routine produced significantly less neutral behaviour than Choice (p<.01), than Instruct (p<.01) and than Contingent Responding (p<.05).

7. What individual differences are there where clients behave differently?

There were two situations in which the group divided in behaviour type. The first was those who show negative behaviour at times compared with those who never show such behaviour: the second was those who show stereotyped behaviour compared with those who never show this. The characteristics of people in each of these examples are summarised below.

Table 7.1: The characteristics of clients who did and did not show negative behaviour

	CLIENT	AGE	SGS	VISION	HEAR	AMBULANT?
1.Negative	5	32	4.5	blind	ok	ok
	6	21	6	p/s	p/h	ok
	21	34	9	ok	ok	no
	22	23	3	ok	ok	no
	26	26	9	ok	ok	no
	28	18	4.5	blind	ok	ok
	totals/medians	24.5	5.25			
2.Not	7	26	3	ok	ok	no
	8	17	1	ok	ok	no
	18	25	1	ok	ok	no
	totals/medians	25	1			

The clients who did not show a behaviour identified as negative were all profoundly physically disabled with little independent movement, hence their relatively lower SGS score.

Table 7.2: The characteristics of clients who did and did not show stereotyped behaviour

	CLIENT	AGE	SGS	VISION	HEAR	AMBULANT
1.Stereo.	6	21	6	p/s	p/h	ok
	18	25	1	ok	ok	no
	22	23	3	ok	ok	no
totals/medians		23	3			
2.Not	5	32	4.5	blind	ok	ok
	7	26	3	ok	ok	no
	8	17	1	ok	ok	no
	21	34	9	ok	ok	no
	26	26	9	ok	ok	no
	28	18	4.5	blind	ok	ok
totals/medians		26	4.5			

The characteristics of clients summarised here do not differentiate between those showing stereotyped behaviour and those who do not.

DISCUSSION

This study was carried out with a small group of staff-client pairs who volunteered or for whom consent could be obtained. How representative the clients were of adults with profound intellectual disability as a whole cannot be estimated, although their relatively low scores on the Schedule of Growing Skills suggest that they were more disabled than the average. It would be even more difficult to estimate how representative this staff group were of staff in general who work with intellectually disabled adults. However, the involvement of staff from the two major services and the inclusion of qualified and unqualified people suggests that a reasonable range of staff were included. This study, then, looked at the interactions between some staff-client pairs under ideal conditions.

Staff were given the opportunity to re-film the Baseline session if they felt it was not typical of the interactions between the client and themselves; one person requested this. Staff and experimenter succeeded in negotiating the interpretation of each client's behaviour within the coding categories without differences of opinion.

The experimental manipulation of the staff interaction strategies was successful in that a naive rater watching the sessions always understood which strategy they were employing. During sessions staff were generally able to make sense of what was required and how it could be applied with their client. A few keyworkers created approaches which resulted in positive responding from fairly unresponsive clients, to their mutual delight. Contingent Responding was a session which caused the most confusion: it needed the most detailed explanations and was the only strategy which any staff wanted to practice before filming.

Calculation of intra- and inter-rater agreements was done on summed data, which could have minimised some of the differences between coders. However, second-by-second analysis can produce results which underestimate agreement as they do not allow for a slight lag in the timing of one rater's judgements. The coding scheme yielded good intra-rater agreements and Kappas described as almost perfect, suggesting that the scheme could be used reliably by somebody familiar with the clients.

There were two types of difficulty in coding. Some clients showed very little change when they moved from, for example, smiling to not smiling. In other cases filming in natural surroundings had resulted in camera angles that were less than ideal for determining direction of gaze. Given that the coder in the inter-rater check had no experience of adults with intellectual disability, received no pretraining in the use of the coding scheme and was asked to rate the three most difficult clients the scores obtained represent an acceptable level of agreement. These results support the use of this data set for drawing conclusions about the effects of these interaction strategies on this group of clients.

The Talk strategy produced more positive behaviour than Baseline and any other condition except for Social Routines. It produced significantly less neutral behaviour than either Choice or Instruct but this did not differ significantly from Baseline. The results show that Talk was very effective in obtaining positive behaviour from a wide variety of clients with different additional disabilities. Many staff in this study reported explaining things to clients while doing them but most did not just talk. A number were surprised by the attention and responsiveness this strategy received.

The number of clients displaying negative and stereotyped behaviour under any condition were small. Talk may have been acceptable to all clients since none displayed negative behaviours during those sessions. Talk may have held clients' attention to events outside of themselves since of the three clients whose repertoire included stereotyped behaviours only one showed this for a relatively short time during Talk. Although not yet convincing, these results do not contradict the suggestion made in the pilot study that an inner-and outer-directed focus of attention or state could be an important aspect of profoundly intellectually disabled adults' social behaviour.

The strategies Choice and Instruct had fairly similar effects on clients' responses. Both resulted in significantly less positive behaviour than either Talk or Social Routine and both produced significantly more neutral behaviour than Talk or Social Routine. A few clients responded to these strategies with more negative behaviour as if they felt under too much pressure to respond under Choice and Instruct. This would be consistent with Wood & Wood's (1984) result that strategies which are highly controlling are least likely to facilitate speech: perhaps such approaches inhibit social responding in general.

These results underline the difficulty clients have in making choices, an important ability if services are to become more responsive to individual need. Separating choice from social interaction may be the solution, as these results suggest that choice combined with social demand may be too complex for many profoundly developmentally disabled adults. The investigation of choice by Glenn & Cunningham (1984) used equipment rather than people to offer profoundly disabled children choice.

Instructing these clients did not facilitate positive responding yet this was a strategy used by a number of staff when asked to spend time interacting with them. It is possible that staff have been influenced by the educational model to such a degree that it dominates all of their interactions with clients. However, an alternative explanation of this finding relates to socio-economic status (S.E.S.). Mahoney (1988) found that mothers of higher S.E.S. preferred to hold conversations with their children while mothers with lower S.E.S. encouraged their children to perform tasks. Staff S.E.S. was not assessed but may have been a factor.

The Contingent Responding strategy was important because it had been recommended by a number of authors as a general rule for interacting with disabled children. Recently this recommendation has been taken up in popular books on profound disability (for example, Ouvry 1987; Brudenall, 1986). Contingent Responding used with these clients resulted in significantly less positive behaviour than either Talk or Social Routine and more neutral behaviour than Social Routine. The three clients whose repertoire included stereotyped behaviour were most likely to do this during Contingent Responding. It seemed as though this strategy was not stimulating enough to help the clients to maintain their attention outside of themselves. McInnes & Treffry (1982) recommend that parents and teachers working with deaf-blind children assume that the child cannot reach outside of themself to interact with the environment without the help of someone else. Perhaps that is equally true for adults with profound intellectual disability.

The final strategy used was Social Routine. This was a strategy which produced significantly more positive responding than Baseline, Choice, Instruct and Contingent Responding; it resulted in significantly less neutral behaviour than Choice, Instruct or Contingent Responding. It was associated with very little negative responding or stereotyped behaviour, although the small number of people showing these behaviours must again be emphasised. This approach was relatively familiar to staff since five of the nine people in the pilot study were using it. It has clear theoretical roots, this study perhaps being innovative in adapting the idea for the staff who felt that tickling games were not age-appropriate and for the clients who were reported not to enjoy such energetic or arousing approaches.

Statistical analysis, especially where groups are small, may fail to highlight the influence of factors demonstrated by only a few of the subjects. An examination of the raw data showed that one of the nine clients increased their positive behaviour under Contingent Responding. She was not obviously less disabled than the others and so the reason for her responding so differently was not clear. Tables 7.1 and 7.2 give information about the group where they were divided by negative behaviour and stereotyped behaviour. The absence of negative behaviour did appear to be associated with profound physical disability: there were no discernible trends in the information about clients to explain their stereotyped behaviour.

All of the results discussed here depend upon the validity of the outcome measures: positive, negative, stereotyped and neutral responding. The classification of client behaviour under these four categories was discussed in Chapter 6. This study has produced no results to question that classification but because stereotyped and negative behaviours occurred at a low rate the categorisation may still be debated.

CONCLUSIONS

This study investigated interactions between a group of profoundly intellectually disabled adults and their keyworkers. Sessions were planned to investigate interaction at its best rather than at its most representative. Staff were asked to vary their strategies and were found to be able to do so. The coding scheme devised to assess the effects of those strategies upon a heterogeneous group of clients was found to be reliable. The results suggest that talking to clients and developing social routines with them are associated with increased positive behaviour. Social Routines in the form of tickling games are relatively well known: the adaptation of this approach to end in other ways was more innovative.

Two issues stood out for further enquiry. The first was a more detailed examination of Contingent Responding - why was it unsuccessful for all but one of the clients? It is possible that the low developmental ages of this group of clients was the key factor here and that the strategy should be investigated with a less profoundly disabled group. The second was a more detailed investigation of the Talk strategy - what are the key features of talking to clients which result in increased positive behaviour?

CHAPTER 8: FURTHER INVESTIGATION OF PROFOUNDLY INTELLECTUALLY DISABLED CLIENTS' RESPONSES TO THE STAFF STRATEGY 'CONTINGENT RESPONDING'.

This study repeated the Baseline and Contingent Responding conditions from the previous study with more clients who had a wider range of developmental ages. This allowed a more detailed investigation of Contingent Responding which had been successful with just one of the clients in the previous study. It was carried out with staff-client pairs from one NHS residential unit and from two social services day centres.

AIMS

1. To investigate whether the Contingent Responding strategy results in changes in client behaviour when compared with Baseline, using a larger sample.

2. To investigate whether clients' developmental level is correlated with changes in their behaviour between Baseline and Contingent Responding.

METHOD

EQUIPMENT

As described in Chapter 7.

SUBJECTS

Subjects were obtained from three units: units A & B were those previously described, Unit C was another special care section of a social services day centre. Consent was obtained from staff and next of kin as before.

In Unit A staff changes and client illness resulted in filming being carried out with 4 staff-client pairs. Two of the members of staff had taken part in the pilot study but not the investigation of staff strategies, the other staff had not been on the unit at that time. On Unit B the same members of staff who had taken part in the Strategies experiment agreed to take part again with the exception of one person who had left. None of the new members of staff wished to take part. Some Unit B staff asked to work with more than one client as they had found the previous experiment helpful.

In Unit C all of the staff members were approached as described before, being given the opportunity to see themselves on videotape. All of the staff consented and the next of kin of the profoundly disabled people were approached by letter. This resulted in a further 7 staff-client pairs being identified, one member of staff electing to work with two clients.

The 16 staff-client pairs who took part in this investigation are listed in Appendix A as follows:
9,10,11,12,13,14,15,16,17,19,20,23,24,25,27 & 29.
Details of the clients' abilities on the Schedule of Growing Skills are given in Appendix B; details of the clients disabilities and characteristics are given in Appendix C and details of the behavioural classification for the coding scheme are given in Appendix D. The following information summarises these individual details.

<u>The client group</u>

N=16

Age: range=16-38 years, median=21.5 years.

Developmental ages:
a) expressed as the median of their attainments on the Schedule of Growing Skills (S.G.S.).
Range=3-15 months, median=9 months.
b) from the interactive social skills section of the S.G.S.
Range=3-24months, median=9 months.

Additional disabilities:
Blind/partially sighted 5
Hearing impaired 1
Unable to move body through space 4
Partially physically disabled 4

No additional disability 5

Self-injury:
Two people injured themselves at times, one severely enough to have his arms restrained in gaiters when unattended.

<u>The staff group</u>

N=13

All had known the client for at least 3 months. Two members of staff held qualifications in nursing and a third held a social work qualification. The remaining 10 members of staff held no relevant qualifications.

DESIGN

This investigation again used an own-control design where subjects' behaviour under Baseline conditions was compared with their behaviour under the Contingent Responding condition.

1. The dependent variables.

These were the set of behaviours agreed for each client indicating Positive, Negative, Stereotyped, Neutral or Uncodable behaviours as described in Chapter 7. The coding scheme was agreed with each keyworker after filming, through discussion of each key event as keyworker and experimenter watched the videotapes.

2. The independent variable.

The CONTINGENT RESPONDING variable was used as described in chapter 7.

3. Reliability.

All sessions were coded by a third rater who had been trained in use of the coding scheme on the tapes of two clients from the previous investigation. Intra-rater agreement was assessed by this rater re-scoring the results for 3 staff-client pairs at least two months after the first analysis. Inter-rater agreement was assessed by the experimenter checking the results of 3 clients. The clients to be re-rated were nominated at random by a third party. A record of which clients were included in which reliability check is in Appendix A.

PROCEDURE

Each staff member was asked to interact with their client in any way they felt appropriate, as described for the baseline session in Chapter 7. The baseline was re-filmed for one pair as the keyworker felt the first session was not typical of her client's behaviour. Filming was done in the clients' bedroom for those in the residential unit, and in a quiet room familiar to the client in the two special care units.

Each staff member then held a Contingent Responding session with the client, as described in chapter 7.

All sessions lasted for 3 minutes and were filmed no closer than one in the morning and one in the afternoon. The sessions for each pair were filmed within the same week.

RESULTS

The following questions were asked of the data.
1. Is the coding reliable?
2. Does Contingent Responding result in a change in clients' positive behaviour?
3. Does Contingent Responding result in a change in clients' negative behaviour?
4. Does Contingent Responding result in a change in clients' Stereotyped behaviour?
5. Does Contingent Responding result in a change in clients' neutral behaviour?
6. Do changes in positive behaviour or in stereotyped behaviour correlate either with clients' median score on the S.G.S. or with their interactive social skills score from the S.G.S.?
7. Is the occurrence of stereotyped behaviour associated with any other client characteristics?

1. Is the coding reliable?

The original codings were compared with the reliability checks second by second, entering the time spent in each behaviour into an agreement matrix.

a) Intra-rater agreement

The level of agreement about client behaviour for both the Baseline and the Contingent Responding conditions were calculated separately. Both agreement percentages and Cohen's Kappa are given, with Landis & Koch's (1977) description of the level of agreement measured by Kappa (see chapter 7 for details).

Client	condition	%Ag.	Kappa	Landis & Koch(77)
10	b	84%	.75	substantial
10	cr	78%	.66	substantial
16	b	91%	.8	substantial
16	cr	72%	.45	moderate
23	b	98%	.96	almost perfect
23	cr	92%	.88	almost perfect

b) Inter-rater agreement

Client	Condition	%Ag.	Kappa	Landis & Koch
13	b	99%	.66	substantial
13	cr	74%	.53	moderate
15	b	93%	.9	almost perfect
15	cr	99%	.97	almost perfect
19	b	81%	.53	moderate
19	cr	87%	.43	moderate

The remaining questions all refer to raw data supplied in the following table.

TABLE 8.1: The amount of responding in seconds of each client under each condition.

	Baseline					Cont.Responding				
C	+	-	S	N	U	+	-	S	N	U
9	64	0	0	106	10	7	0	100	54	19
10	20	29	48	82	1	20	12	102	43	3
11	64	0	87	27	2	35	0	93	45	7
12	94	0	0	79	7	7	3	0	168	2
13	0	0	0	177	3	47	0	12	120	1
14	28	0	0	150	2	37	0	0	142	2
15	45	49	0	78	8	4	141	0	33	2
16	69	0	0	110	1	48	0	131	0	1
17	63	0	10	105	2	69	0	96	13	2
19	123	13	0	40	4	10	0	20	146	4
20	7	50	0	115	8	5	0	153	13	9
23	68	0	5	105	2	71	0	36	71	1
24	32	7	17	120	4	27	0	8	142	3
25	42	11	0	121	6	76	3	0	99	2
27	54	0	29	89	8	47	0	65	66	2
29	29	0	83	67	1	19	0	90	63	8
Med	49.5	0	0	105		31	0	50.5	64.5	

2. Does Contingent Responding result in a change in clients' positive behaviour?

Results were analysed using a Wilcoxon matched pairs signed ranks test (Siegel & Castellan, 1988), using a two-tailed test of significance. There was no significant difference between the amount of positive behaviour in these two conditions (T=34, z=-1.48).

3. Does Contingent Responding result in a change in clients' negative behaviour?

There were too few instances of negative behaviour for analysis.

4. Does Contingent Responding result in a change in clients' stereotyped behaviour?

Results of the 12 clients who showed stereotyped behaviour were analysed using a Wilcoxon matched pairs signed ranks test, using a two-tailed test of significance. This showed a significant increase in stereotyped behaviour under the Contingent Responding condition (p<.005).

5. Does Contingent Responding result in a change in clients' neutral behaviour?

Results were analysed using the Wilcoxon as described above. There was no significant difference (z=-1.73).

6. Do changes in positive behaviour or in stereotyped behaviour correlate either with clients' median S.G.S. score or with their interactive social skills score on the S.G.S.?

The Spearman rank-order correlation coefficient (Siegel & Castellan, 1988) was used to measure the associations between the amount of change in behaviour and their developmental age, using the correction for ties.

a) Amount of positive behaviour correlated with median S.G.S. This showed no significant correlation between the two measures (rs=-0.043).
b) Amount of positive behaviour correlated with interactive social skills score.
This showed no positive correlation (rs=0.16).
c) Amount of stereotyped behaviour correlated with median S.G.S. score for the 12 clients who showed stereotypy. This showed no significant correlation (rs=-0.01).
d) Amount of stereotyped behaviour correlated with clients' social-interactive skills score on the S.G.S. This showed no significant correlation (rs=0.3).

7. Is the occurrence of stereotyped behaviour associated with any

other client characteristics?

Table 7.1: Characteristics of clients who did and did not show stereotyped behaviour

	CLIENT	AGE	SGS	VISION	HEAR	AMBULANT
1.Stereo.	9	25	12	ok	ok	no
	10	24	12	ok	ok	ok
	11	38	3	ok	ok	ok
	13	22	15	ok	ok	ok
	16	21	9	ok	ok	no
	17	28	6	ok	ok	no
	19	26	6	blind	ok	ok
	20	21	6	p/s	p/h	ok
	23	19	12	ok	ok	ok
	24	37	3	ok	ok	ok
	27	21	9	p/s	ok	no
	29	20	6	ok	ok	ok
totals/med.s		23	7.5			
2.Not	12	26	12	p/s	ok	ok
	14	18	6	ok	ok	no
	15	19	15	ok	ok	ok
	25	16	9	ok	ok	ok
totals/med.s		18.5	10.5			

None of the variables investigated here distinguish between the clients who do and do not show stereotyped behaviour.

DISCUSSION

This study was carried out with 16 staff-client pairs working in three different services for adults with profound disability. Sessions were carried out when clients were well in conditions as close to ideal as could be found. These results describe the effects of the strategy Contingent Responding upon a particular group of clients under relatively special conditions.

The reliability checks showed that the rater was generally able to maintain a high level of intra-rater agreement although the figure for the Contingent Responding session for client 16 is a bit low. This concerned a very profoundly physically disabled client. Difficulties in coding particular types of clients are developed in chapter 11 when all aspects of these experiments are discussed. The inter-rater agreement figures are within acceptable limits given the subjective nature of social judgements with this group. As the results depend upon the difference between the clients' behaviour in two conditions using the first rater's codings, any errors in rating should be consistent and therefore controlled to a degree.

This set of agreement figures suggest one limitation of Cohen's Kappa. The inter-rater agreement percentage for the baseline session for client 13 was 99% but Cohen's Kappa reduces this to .66, described as only a 'moderate' level of agreement. This appears to be the consequence of too much agreement. The codes are recorded in a five by five matrix but if, as in this case, there is such unanimity between coders that only two of the codes are used the calculation of Cohen's Kappa is mathematically reduced to an analysis of a two by two matrix. In this situation the supposed correction for guessing becomes very high, resulting in a Kappa figure which seems inappropriate.

This investigation of Contingent Responding confirms the suggestion in chapter 7, that the strategy was not generally successful in facilitating positive behaviour in this sample. It was carried out with a group of adults who had more skills than those in the last study as measured by the S.G.S. (a median developmental age of 9 months rather than 4.5 months of the previous group) but with similar results. The only statistically significant result obtained was that Contingent Responding was most likely to result in increased stereotyped behaviour from people whose repertoire included it, in this case 12 of the 16 people studied. However, inspection of the raw data shows that Contingent Responding produced increased positive behaviour in five individuals and so it should not be completely dismissed.

Why should stereotyped behaviour increase under this condition? Behaviourists might say this was because it had been reinforced yet all of the client's behaviour was reinforced in this condition and there is no explanation of why reinforcement would work selectively. Previous studies have shown that clients are less responsive to external events when engaged in stereotypy, not more. Previous studies have also shown that stereotypy decreases when environments are enriched and so perhaps the clients generally experienced Contingent Responding as unstimulating. The idea that stereotyped behaviour is linked with an internal focus of arousal is examined and discussed further in Chapter 10.

The idea that responses should be client-centred has both psychological and philosophical roots, as was discussed in chapter 6. It is possible that this is an important aspect of interacting with this client group but that it only has an effect on the majority of clients when combined with another strategy. That additional strategy may engage the person's attention outside of themself or may help them to emit more behaviour to which their interactor can respond.

The question of correlation with developmental age arises from the claimed utility of the developmental model for profoundly intellectually disabled adults. Glenn and Cunningham (1984) found that a developmental age of 5 and 9 months respectively predicted whether profoundly disabled children would be able to make simple or complex choices. Developmental age might be similarly useful in describing differences between adults in this sample.

In this study, median developmental age was investigated for correlations with both the change in positive behaviour and the change in stereotyped behaviour in the two conditions; no significant effect was found. Since the S.G.S. is divided into a number of sub-scales it is possible to correlate score on one of those scales against behaviour change. The interactive social skills scale seemed most relevant and so this was investigated for a correlation with change in positive and in stereotyped behaviour, again with no significant effect found.

There are three possible explanations for this lack of correlation with developmental age. The first is that developmental age is not a useful concept in understanding profound intellectual disability. The second is that the assessment was wrong or inadequate. The third is that factors associated with the keyworker were confounding the result.

The S.G.S. was designed for infants from birth to three years and should therefore assess skills within the range of profoundly intellectually disabled adults if the model of child development is accepted. Based on Sheridan's STYCAR sequences, Bellman & Cash (1987) state that assessments using the S.G.S. gave developmental ages for a sample of 100 non-disabled children which were significantly correlated with those obtained using the Griffiths Mental Development Scales. Ratings for 25 children on the S.G.S. and the Griffiths in a clinical situation were also significantly correlated. It therefore seems reasonable to assume that the scores obtained on the S.G.S. were an appropriate test of the developmental model.

The suggestion that keyworker factors interact with client attributes seems likely and is developed in the next chapter.

The investigation of individual differences concerning stereotyped behaviour yielded no clear distinctions between the two groups. The results have little in common with those from Table 7.2 in Chapter 7 although they concern the same issue. For example, in this chapter the people who did not show stereotyped behaviour were older whereas they were the younger of the two groups in Chapter 7; in this chapter a quarter of the people who showed stereotypy were non-ambulant whereas two thirds were non-ambulant in the previous study. This inconsistency would be expected if stereotyped behaviour was understood to be a function of the person in interaction with their environment and not solely an individual attribute.

CONCLUSIONS

The reliability check on one of the data sets suggested that there are situations in which Cohen's Kappa gives a misleading description of the level of agreement between two sets of codings. This supports Uebersax's (1988) contention that it is not reasonable to assume that raters are guessing and that making such a correction in this situation leads to an unacceptably low reliability estimate.

This investigation of the strategy Contingent Responding found that it had no significant effect on the clients' responding except that those who showed stereotyped behaviour were more likely to increase it. Focussing attention towards making responding contingent on the client may have been misplaced. It may be more important to find out about the intervention strategies it must be combined with. These results suggest that staff have to rely largely on their own resources when trying to create and maintain an interaction, clients providing them with relatively few opportunities to respond rather than to lead.

This investigation did not find client behaviour to be correlated with developmental age or attainment. Clearly, somebody with a developmental age of 10 years would have interacted differently and this result only refers to this sample. But developmental age on the S.G.S. did not distinguish between people in this group of profoundly intellectually disabled adults when the amount of positive behaviour and the amount of stereotyped behaviour shown during interaction were investigated. Three explanations of this result were proposed.

CHAPTER 9: A COMPARISON BETWEEN THE PRECEDING INTERACTION STUDIES AND FUNCTIONAL ANALYSES OF PROBLEM BEHAVIOUR

The object of this chapter is to characterise more clearly the position being put forward. The discussion is introduced by reference to the philosophy of science. Some literature on the functional analysis of stereotyped and self-injurious behaviour is then reviewed, as this concerns a related topic and provides a contrast for the studies reported in the previous three chapters. Comparison between the two sets of investigations forms the third section. The chapter concludes with an outline of a model for understanding and perhaps reconciling different views in psychology.

It may be useful to reiterate the aims of these investigations. Firstly, they were carried out to uncover themes in carer-client relations which would help carers to interact with their profoundly disabled clients more effectively and meaningfully. Secondly, they were intended to contribute to a new conceptualisation of profound intellectual disability in adults.

THE PHILOSOPHY OF SCIENCE

Concepts, models and theories are ideas which recur throughout this thesis. One reason that their discussion is problematic is because the terms are intermingled in different ways throughout the psychological literature.

Karl Popper (1963) emphasised the development of theories and the importance of their falsifiability. He stressed that science must continually grow and progress; authors of refuted theories should be lauded for their contribution to the growth of knowledge, not pitied for their failure. He made the following statement: "You will have noticed from this formulation that it is not the accumulation of observations which I have in mind when I speak of the growth of scientific knowledge, but the repeated overthrow of scientific theories..."(p.215).

Despite advocating the value of refutation Popper argued against a purely logical analysis of theories, observing that dogmatic defense of a system until it is conclusively disproved represents "the very reverse of that critical attitude which in my view is the proper one for the scientist....If you insist on strict proof (or strict disproof) in the empirical sciences, you will never benefit from experience, and never learn how wrong you are."(1959, p.50). In The Logic of Scientific Discovery Popper again stated that analysis and refutation were not the only criteria for science: "Among the real dangers to the progress of science is not the likelihood of its being completed, but such things as lack of imagination...a misplaced faith in formalization and precision ...or authoritarianism in one or another of its many forms."(1963, p216).

Popper discussed the difference between his position and that of the positivists. He saw the problem as a repeating one between the 'leaders of the latest positivistic assault' and philosophers, centring on different views on the value of experience. "Its upholders (positivists) fail to notice that whenever they believe themselves to have discovered a fact, they have only proposed a convention."(1963, p.53). Williams (1983) suggests that the term 'positivist' has become a term of abuse used only by opponents of the position that human knowledge develops through the exclusive reporting of observable facts. He noted that the debate was an important one but 'somewhat empty' when those who defend the position never use the term: this tended to distance the conflict and prevent its clarification.

Popper (1963) drew a distinction between empiricist and empirical scientists. Popper described the "naive empiricist" as one who "thinks that we begin by collecting and arranging our experiences, and so ascend the ladder of science....however rich a collection of statements might be assembled in this way, it could never add up to a science. A science needs a point of view, and theoretical problems." (1963, p.30). He described the development of theories occurring through a process of logical deduction from an original idea: new ideas contain an intuitive, creative or irrational element. The term 'empirical' is reserved for the experimental testing of such conceptual systems.

The accumulation of information as a scientific activity has been a frequent target for criticism. Popper's position was supported by Bunge (1963) who stated that "Scientific theories are systems, not just heaps, of corrigible propositions (hypotheses)." (p.100). Bunge's criteria for an adequate theory are exemplified by Festinger's (1954) Theory of Social Comparisons and by Kelly's (1955) Theory of Personal Constructs.

Yet much of current applied psychology consists of accumulating experimental findings without an overarching theory. The growing literature described as health psychology would be one example, Argyle's experiments and books on social behaviour another (e.g. 1985, 1988). They do test hypotheses and models but these are not fully constructed theories and many of them are derived from observation alone. This is an unacceptable basis for a theory according to Popper and also to Harre, who observed: "Mendel's monks could classify and count peas, but more than sharp eyes and a couple of baskets are needed to discern genes." (1981, p.6).

Argyle interchanges simple ideas with models and theories so that the philosophical basis of his position is not clear. For example, in bodily communication (1988) he writes :

> "It is sometimes said that theory is weak in the case of non-verbal communication, perhaps because the popular theories in social psychology do not have much application here....First we will explore the theory that bodily communication is really a kind of language - the 'linguistic model'." (p.290).

The exchange between models and theories occurs a few pages later when Argyle describes social interaction:

> "Theories of social interaction deal with the behaviour of two or more individuals. The author's social skills model is an example." (p.298-9).

The transition between the terms 'theory' and 'model' suggests that Argyle sees little difference between them. In other texts he merely raises an idea, for example the view that social behaviour is governed by rules (1985), without discussing the status of this idea. The confusion between ideas and theories occurs again when Argyle discusses explanations of reasons behind women being more effective decoders of non-verbal signals than men.

Popper (1963) devoted less attention to models than he does to theory development. He described a model as varying the initial conditions of the world and interpreting the results of such changes. A model does not need to be faithful to the initial conditions of our world, unlike a theory. A second sense in which he used the term 'model' was to describe a system of axioms which may be regarded as conventions but which could not be seen as a linked system of scientific hypotheses.

Thines (1980) provides an exposition of models and theories as they apply to psychology. He noted the the word 'model' is ambiguous and used by psychologists in many different ways. Thines stated that this was dangerous as there seemed to be no criterion of precision which allowed us to understand what stage in the systematisation of knowledge had been achieved when the term model was used. He wrote: "Reductionism is still very much alive and ... many of our so-called models are often based on assumptions concerning subjective components of behaviour which have not developed much since Wundt's epoch...The above instance may at least help us to become aware of a dangerous illusion; viz, the assumption that a model is always at the outset a purposeful and logically well-structured set of propositions." (p.360).

Thines described a model as a tentative representation of some kind, the suggestion of a link between one system and another. This may be interpreted to mean that psychologists use models to generate research hypotheses as if (for example) human behaviour were animal behaviour, but without losing sight of that 'as if' quality. This is consistent with Popper's (1963) proposition that a model does not need to be concerned with the accuracy of the initial conditions. Thines' view of a theory, based on Bunge (1973), is that it is a developed system of interlinked ideas which have accuracy, congruence and heuristic value. His detailed discussion argues that a theory may be developed from one or more models but that it exists at a more accurate, systematic and comprehensive level of explanation.

Why is the absence of theory a problem? Firstly, too many accumulated facts become unusable. Argyle & Kendon first proposed the experimental analysis of social performance in 1967. Over the last 20 years Argyle and others have accumulated such a wealth of information on social behaviour that it is no longer clear how such an analysis should be carried out; similarly, social skills training programmes get longer and longer as people attempt to include all of the experimental findings.

Secondly, it is questionable what compiling facts contributes towards understanding people. Argyle & Henderson (1985) provide the following information: how to behave towards one's neighbours (12 rules, including give eye contact, respect their privacy, keep confidences,) and how to behave towards one's spouse (25 rules, including respect the partner's privacy, keep confidences, give eye contact). Important differences between these relationships seem to be missed from this type of analysis.

Thirdly, the absence of a theoretical framework provides no boundaries to the accretion of information. Without such structure to the investigations there is always another experiment which could be added, a further adaptation made to the way in which the data is summarised. The position cannot be refuted if there is no coherent position.

Using these criteria, can social constructionism be accepted as a theory? Mead (1934) originally proposed a theory which had an interlinked system of ideas with congruence and some demonstrated accuracy which has certainly proved to be heuristic, spawning research activity into diverse topics such as lesbianism, the generation of ideas in scientific research teams and the social construction of personal identities. However, research in social constructionism in the past decade has led to it becoming less coherent as a theory.

Some social constructionists may not accept the question as relevant as they describe being part of "the dawning of a new age of scholarship, one marked by a far greater charity towards disparate voices, sharpened by a sensitivity to the processes by which knowledge claims are made and justified, with a heightened moral concern, and a keener appreciation of the communal character of understanding." (Shotter & Gergen, 1989, p.x). However, the approach has many of the qualities attributed to scientific theories. It considers information at an abstract as well as an observational level and delineates a coherent area of inquiry: "The extent to which abilities and processes, formerly located in individuals, are now seen as products of human community." (frontispiece, Shotter & Gergen, 1989).

Harre (1981) develops scientific thinking from a social constructionist perspective by disputing the separation of theory from fact. Harre described the interrelationship between two conceptual systems, an analytical schema and an explanatory schema. The analytical schema reveals which items are to be included in the field of interest; while explanatory schema propose mechanisms by which perceived orderliness may occur.

Harre described a mature and successful science as one in which these two systems were coordinated. He gave examples from the history of science to show that new developments arise from a recognition that both the experimental and the conceptual equipment is incapable of revealing the mechanisms generating observed orderliness. Valsiner's (1987) criticism of fashionable ideas being described as theories, and his assertion that progress occurs through the co-ordination of theory and observation, develops Harre's position.

FUNCTIONAL ANALYSIS

The effect of theoretical stance on research activity can be illustrated by contrasting the studies reported in the previous three chapters with work on problem behaviour. The latter are referred to as functional analyses because the analysis is intended to identify the functions which are served by particular behaviours, for example avoidance of demand or access to attention.

Iwata et al's (1982) classic study looked at the amount of self injurious behaviour shown by children in different circumstances. Four situations were set up in an experimental room: the child alone in an empty room, the child and an experimenter in a room with toys, the experimenter using social disapproval when the child self-injured and, finally, the experimenter putting the child under demand by asking them to do tasks beyond their ability. Such functional analyses are generally referred to as the analogue approach as it is assumed that these situations are analogies of the person's experience.

Sturmey et al (1988) extended analogue analysis to stereotyped behaviour in three adults with profound disabilities. There were behaviour changes in two of the clients which showed the consistent effects of academic demand and being alone respectively. However, the increases in stereotyped behaviour under these conditions were relatively modest. One of their subjects, as with three of Iwata et al's nine subjects, seemed to be unaffected by the four situations. Sturmey et al discussed both sets of results, suggesting that the clients whose negative behaviour showed little change may have been unable to distinguish between the environments or that their behaviour may have been influenced by variables not present in the analysis.

Sturmey et al (1988) also discussed the difficulty of selecting activities which were functionally equivalent to naturally occurring environments, giving the example of a profoundly disabled woman who never handled toys spontaneously. For her, the'academic demand' situation may have seemed no different from the 'free play' sett~~i~~ng in which toys were handed to her every 30 seconds. Moreover, the selection of toys may be crucial to the incidence of stereotyped behaviour, as they reported a study showing that some toys are associated with higher levels of stereotyped behaviour than others in autistic children.

Axelrod (1987) noted in his review that not all functional analyses identify causes of self injurious behaviour and that so far there have been relatively few examples published. He commented that functional and structural analyses "rest on the assumptions that the factors controlling a behaviour can be identified and manipulated." (p.166).

Carr & Durand have developed the idea that behaviour problems in general, both assaults on others and self injury, may be regarded as functionally equivalent to other forms of communication. They suggest that a functional analysis should be most concerned with two of the above situation types: when the individual is under demand and when they are in a situation of low adult attention. Analysis concentrates on which of these two situations affects individuals, intervention focussing on providing them with alternative means of achieving those ends. This intervention has been named functional communication training (Carr & Durand 1985) and has been applied to stereotyped behaviours (Durand & Carr 1987) as well as self injury and aggression (Bird et al 1989).

Repp et al (1990)'s review takes a very positive stance on functional analysis, describing it as an important development because it ensures that analysis precedes intervention. Their concluding comments are a strong recommendation of the technique: "The utility of such an approach in deriving theory-based interventions has been demonstrated in recent studies, eg Durand & Carr, 1987;....we advocate this approach to the treatment of all problem behaviours..."(p103). Although Repp et al use the word 'theory' it had not been used by Carr & Durand. Different uses of this term have already been identified as creating an obstacle in debate between psychologists following disparate schools of thought.

COMPARISON BETWEEN THE STUDIES

Doise (1986) suggested that a hypothesis only has meaning through its articulation with other hypotheses. Juxtaposing these different studies helps to clarify their purpose and contribution.

The research reported in chapters 7 and 8 and the functional analysis of stereotyped and self injurious behaviours have a similar structure in that interactions between two parties were experimentally varied and analysed. This structure is also present in the studies of interactions between teachers and deaf children carried out by Wood & Wood (1984), reported in chapter 4. Detailed examination of them found that they differed in four major ways: their purpose, the derivation of the strategies used by the staff, their perspective on the clients and on the interacting adult. These are elaborated below.

1. Purpose of the investigations.

The functional analyses of self injurious behaviour carried out by Iwata et al (1982) Durand & Carr (1987) and Sturmey et al (1988) were designed to underpin treatment interventions which would suppress these 'aberrant' behaviours. Lewis and Baumeister (1982) had this to say about such approaches: "Methods for suppressing stereotypies usually have involved behavior-shaping techniques derived from operant principles. It is our view, however, that treatment studies of this nature,..., do little to elucidate the nature of the behaviour..."p152.

The investigation carried out by Wood and Wood (1984) was part of a set of investigations into the way that deaf children learn. These were rooted in the ideas of Vygotsky and of Bruner on the role of adult-child interaction on learning and development.

The investigations reported here were designed to find out about the nature of the relationship between keyworking staff and profoundly disabled adults. A social constructionist view of that relationship was taken, in other words it was assumed that behaviour in a social context was the outcome of an interaction between two individuals and not a 'fact' about only one of them. There was a second goal of contributing towards the development of a model of profound disability as it had been argued that the model of child development was not suitable.

2. Derivation of the strategies used by staff.

Sturmey et al (1988) describe the ideas behind the different strategies as having been derived from Carr's proposed motivations for self-injury: positive or negative external reinforcement, or positive or negative internal reinforcement.

Wood & Wood (1984) derived their teacher strategies from a linguistic analysis of free discussion sessions, an ethological approach.

The present study derived the staff strategies quasi-ethologically from sessions which were described in the pilot study. It is unusual to intervene and "set up" interactions when taking an ethological approach. In this instance it was necessary because of the repeated finding in the literature of staff-client interactions which are short and which occur infrequently. It seemed that progress would be slow if observations continued to be collected in entirely natural circumstances; the inquirer is justified in intervening to some degree. Here the intervention was minimised to that required to obtain examples of interactions for analysis.

3. Perspective on the client

a) Individualism

This is not made explicit in the functional analyses but the individual view of Behaviourist studies is evident, that is, that the client is the one who "has" self injurious or stereotyped behaviour and not the client in interaction with their own particular environment. Behaviourists may object to this statement by pointing out that environmental variables are exactly what the Iwata et al method seeks to investigate. However, since the sessions are held in strange rooms with strange people on nearly every occasion (the intervention study by Bird et al, 1989, is an exception) this is not a position that can be justified easily.

In the Wood & Wood (1984) study the client's behaviour is assumed to be inextricably bound up with their teacher's behaviour and both are subject to study and analysis.

The current studies assumed that behaviour is the outcome of an interaction between client and keyworker. The client's relationship with their keyworker was assumed to be of prime importance in facilitating responsiveness and so members of staff had to have had three or more months working with the client before they were included. The operation of environmental influence was facilitated by carrying out sessions in the client's own room. The studies reported so far were preliminary to an interactive analysis which occurs in chapter 10. They were carried out partly to identify what type of interaction should be subjected to such a searching analysis.

b)Holism

The functional analysis only concerns the incidence of negative behaviours. Some functional communication training studies also record the child's engagement in academic tasks. However, neither analysis attempts to investigate the clients' behaviour as a whole.

The linguistic analysis in the Wood & Wood (1984) study is comprehensive, being carried out on all utterances made by teacher or child during the session.

The analysis of the clients' behaviour in the current study is comprehensive in that all session time is accounted for.

4. Perspective on the interacting adult.

As was intimated above, the functional analyses do not assume that the identity of the person in the room with the client is pertinent to their inquiry. History, familiarity, relationship are not thought to be relevant variables. Nor are the staff given any latitude to interpret the strategies. Only Bird et al (1989) used staff who had had contact with the client rather than experimental staff. Their intervention study demonstrated generalisation across people, settings and time as long as all staff were familiar with the behavioural procedures (and, perhaps, the client).

The Wood & Wood study worked with volunteer teachers and their pupils; the teachers were given considerable leeway concerning the conduct of sessions.

The present study placed the relationship between client and keyworker centrally within the design. The coding scheme is based on the keyworker's interpretation of the client's behaviour. Also, staff were encouraged to interpret and adapt each of the strategies so that they became appropriate for their client and natural for themselves.

RECONCILING DIFFERENT PERSPECTIVES

Shotter & Gergen's (1989) hope that a new age of greater charity toward different positions is dawning requires that ways of doing so are found. Doise (1986) proposes approaching this from the idea of different levels of explanation. He argues that this is particularly useful for applied psychologists as attempting to construct a more complete explanation of reality requires the enrichment of any given theoretical approach by other theories.

This way of viewing psychological knowledge has been independently developed by Doise and by Valsiner (1987, whose work was detailed in chapter 1). Both authors propose four levels of explanation or frames of reference for psychological investigation; however, Doise is more concerned with the relationship between levels than is Valsiner. In the terms discussed in the first section of this chapter Doise's proposed levels of explanation would be a model, although he does not use the word.

These levels of explanation concern the way that the individual is studied, the focus of attention being either within the person, between them and other persons, or between them and their wider social environment. This invites consideration of the way in which individuals are seen from different perspectives. Many studies look at client responses to staff strategies as if the clients are encapsulated individuals but such individualism is a matter of considerable debate in social psychology, particularly in Europe.

The prevalent view of personhood has been tellingly described by Geertz:

> "The Western conception of a person as a bounded, unique, more or less integrated motivational and cognitive universe, a dynamic center of awareness, emotion, judgement and action, organized into a distinctive whole and set contrastively against other such wholes and against a social and natural background is, however incorrigible it may seem to us, a rather peculiar idea within the context of the world's cultures." (quoted by Sampson, 1989, p1).

Sampson (1989) describes challenges to Western individualism coming from cross-cultural studies, from feminism, from social constructionism, from systems theory, from critical theory and from deconstructionism. He suggests that changing conceptions of personhood amount to a Kuhnian paradigm shift in that major cultural change produces it and it then sustains the new position. He concludes that there is an interpenetration in the person-society relationship in which neither has primacy and recommends that psychologists refocus their understanding to study that relationship.

Landesman-Dwyer & Sackett's (1978) study on profoundly disabled people provides an opportunity for this 'refocussing' where the degree to which a person is an encapsulated individual can be questioned. They found that participants' scores on the Bayley Scales did not change following the stimulation project even though scores on other criteria did (for example, engagement with the environment). Incorporating Baumeister's (1987) suggestion that intellectual disability has both hardware and software implications can also assist in interpreting this result. Baumeister suggested that there is a structural limitation imposed on an individual by the type or degree of physical damage they have, but that within the limits imposed by this damage - the "reaction-range" - the way that the person behaves is influenced by the people around them, their learning opportunities and their history.

This way of seeing profound intellectual disability gives a place to the type and extent of damage existing at the individual level but also allows for a socially constructed expression of the disability. Landesman-Dwyer & Sackett's results could then be seen as suggesting that the Bayley taps structural components of disability while the other measures looked at socially constructed expression of that disability.

Baumeister's perspective can also be extended to the results of the studies described in the previous two chapters. Analyses of individual differences suggested that profound physical disability was associated with absence of a negative response, while no individual differences were found to be associated with the presence or absence of stereotyped behaviours. This may be explained by seeing the first result as a structural limitation operating at the individual level for people with additional profound physical disability while the stereotyped behaviours may be socially constructed expressions of profound disability regardless of its type.

SUMMARY AND CONCLUSIONS

This chapter has emphasised the influence of theoretical position on data collection. It has been argued that explicit theoretical positions are essential to the development of science as a point of view is required for ideas to be elaborated, challenged and overthrown. Many psychologists describe their work as being based on models or theories but they are not referring to theories which would be accepted as such by philosophers.

The approach taken towards both the clients and the keyworkers in this study was designed to contribute at a theoretical level. It took a socially constructed view of the interaction between the individual and their social environment which means that any aspect of an individual's behaviour was assumed to be the outcome of an interaction between factors contributed by both parties. This is the main way in which both this and Wood et al's work differed from functional analyses.

Another virtue of theories was argued to be setting the boundaries of an enquiry. The application of Baumeister's hardware-software distinction helped to clarify the boundaries of a socially constructed enquiry into interactions. This suggested that profound physical disability can be an overriding 'hardware' or structural limitation which placed absence of negative behaviour outside the ambit of an analysis based on social interaction.

Using the model of different levels of explanation to make sense of alternative psychological approaches may help in the development of a comprehensive view. In the long term it may allow the integration of results of studies of social interaction with data on staff-client contact derived from functional analyses. However, it seems premature to attempt such an integration at the moment, the ideas being different on each of the four criteria discussed and relatively unformed on both sides.

Clarification of the socially constructed nature of many aspects of profoundly intellectually disabled people's behaviour invites examination of the mutual influence between the person and their keyworker. This is considered in the next study.

CHAPTER 10: THE ANALYSIS OF INTERACTIONS DURING "TALK" SESSIONS BETWEEN ADULTS WITH PROFOUND INTELLECTUAL DISABILITY AND THEIR KEYWORKERS.

Arousal and stereotypy were identified in Chapter 4 as key issues in understanding profoundly disabled adults, where it was argued that the model of child development did not provide the most useful conceptual framework. Both of these issues were discussed in depth in Chapter 6 where the scheme for coding client behaviours in this project was described. It was suggested that this scheme placed the focus of the individual's attention on a continuum of arousal or state.

Landesman-Dwyer & Sackett (1978) showed the variation in responses given by profoundly disabled people from day to day, seen by Sternberg & Richards (1989) as evidence of fluctuation in levels of state or arousal in this group. The design of investigations may need to take these behavioural variations into account whatever their origins.

Interpersonal space has been identified by Argyle (1983) as an important dimension in social behaviour between non-disabled people. It has also been studied by social psychologists investigating interactions between disabled and non-disabled people (Davis, 1964; Katz, 1981). Turn-taking has been another fertile area of investigation between adults and both non-disabled and disabled children (Bruner, 1975; Bunt, 1985).

Studying the process of social interaction was discussed in the methodological review in Chapter 1: one technique which can be used to carry out such an investigation, sequential analysis, was described in Chapter 5. The advantages and limitations of such an analysis were discussed in the last chapter.

The debate between quantitative and qualitative investigations has been reviewed. Landesman-Ramey et al (1989) suggest that there is value in combining the techniques in one study as they can be conceptually compatible while making different types of contributions. Marshall & Rossman (1989) suggest that the qualitative approach is particularly useful when investigating new issues.

Talking with profoundly disabled people was identified in Chapter 7 as a staff strategy associated with an increase in positive responses from clients. That strategy is developed here by investigating such interactions between 20 staff-client pairs; the same sessions were analysed using both quantitative and qualitative techniques. The problem of variation in responding was dealt with by filming five sessions but analysing only the two which keyworker and experimenter selected as the best.

AIMS

1. To analyse client behaviour during social interaction sessions for insights into the nature of profound intellectual disability in adults.

2. To investigate whether interactions between clients and keyworkers show evidence of sensitivity or turn-taking, using quantitative analysis.

3. To describe the behaviour of keyworkers and clients during interaction sessions using qualitative analysis.

METHOD

EQUIPMENT

Sessions were filmed as before. The equipment used to analyse these sessions could play back at infinitely variable speeds: this allowed speech to be heard at some slow speeds. Sequential analysis of the data was carried out on a personal computer using a programme written in GWBasic.

SUBJECTS

Client-keyworker pairs were obtained from Units A, B and C, the same settings used for the Contingent Responding experiment. For this investigation 32 next of kin and 3 residential home managers (when no next of kin was known) were asked to agree to the client participating in the project. Consent was obtained for 29 clients. Twenty-four members of staff were contacted across the three units: 18 people volunteered to take part. Matching keyworkers who had volunteered with clients for whom consent had been obtained brought the sample to 23 pairs. Two clients were subsequently dropped from the project due to illness and one data set was lost due to technical problems, leaving 20 pairs. These are listed in Appendix A as follows: 9,10,11,12,13,14,15,16,17,18,19,20,21,22,23,24,25,26,27,29.

Individual details are found in Appendices A and B. These are summarised for each group below.

<u>The client group</u>

N=20

Age: range 16-38 years, median=23.5 years.

Median developmental age on the S.G.S.
Range=1-15 months, median=9 months.

Additional disabilities:
Blind/partially sighted 6
Hearing impaired 1
Unable to move body through space 6
Partially physically disabled 6

No additional disability 5

Self-injury:
Three people injured themselves at times, two severely enough to have their arms restrained in gaiters when unattended.

The staff group

N=16, four people each choosing to work with two clients.

All had known the client for at least 3 months. Two members of staff held qualifications in nursing and a third held a social work qualification. The remaining 13 members of staff held no relevant qualifications.

DESIGN

This investigation analysed the best of the five sessions held between client and keyworker when the keyworker was talking with the client. Criteria for selection were that the client seemed to show more positive responding and social exchange with the keyworker and because the keyworker had felt subjectively that meaningful exchange had occurred between them. The best two were selected and subjected to two forms of analysis.

A) Quantitative sequential analysis.
Client responses were categorised as before into Positive, Negative, Stereotyped and Neutral. Staff behaviour was coded as talking or not talking.

Sequential analysis of the behaviour of clients as a group was carried out. A second form of sequential analysis explored the responsiveness of staff to client and client to staff within the same second and at one-, two- and three-second lags.

Intra- and inter-rater reliability of the codings for staff and clients was calculated on both sets of recordings for a total of 6 pairs. A record of which pairs had which reliability check is in Appendix A. The whole set of sessions were coded by the third rater, inter-rater checks were done by the experimenter.

B) Qualitative analysis.
Global aspects of social exchange between staff-client pairs were explored by this technique. Systematic methods were used to negotiate an agreed description of staff-client interactions within the following categories: identification of pairs who had limited interactions and of pairs who had animated exchanges, description of overall style, of response types and of interpersonal space.

PROCEDURE

Staff held five three minute sessions with their client in which they spoke to the person. They knew that an earlier experiment had suggested that this was a useful way of interacting with profoundly developmentally disabled adults and that the experimenter wanted to investigate this in greater detail. They were invited to position themselves and the client however they thought appropriate but were asked not to make major changes to this arrangement between sessions. Staff could hold the client's hand or touch if that was usual. Photographs or other objects could not be used during sessions because the investigation concerned the effects of talking directly to clients.

Some staff asked what they should talk about. Discussion of past events was suggested so that there would be many details to recall and describe; staff who had discussed future events had found it harder to talk about them for long. The topic should be of interest to the keyworker themselves so that they could talk fluently.

Sessions were filmed as before, at times when the client was thought to be receptive. No two sessions were filmed in the same morning or afternoon and the whole set for any pair were filmed within two weeks. At the end of filming the keyworker watched the films with the experimenter, agreed which were the best two sessions and the way that the client's behaviours should be interpreted within the coding scheme.

ANALYSIS

Following a check that there was no significant order effect between the first and the last of the set of five sessions the two which keyworker and experimenter felt were the most successful were analysed.

A) The quantitative analysis.

The variables for the clients were those used in the previous three studies, that is the set of behaviours agreed for each client as indicating Positive, Negative, Stereotyped, Neutral or Uncodable behaviours (described in Chapter 7 and given in detail for each client in Appendix D).

The variable recorded for the staff was whether or not they were speaking.

The staff and the client variables were coded separately by the rater who had coded the Contingent Responding tapes. The reliability of these codings was assessed as before, by that rater re-coding the sessions for three pairs nominated by a third party and also by the experimenter coding the sessions for three pairs nominated by a third party at random. Both agreement percentages and Cohen's Kappa were calculated.

The pairs selected for the intra-rater agreements were not random: pairs were included if they had not previously been involved in a reliability check and if they represented people from early, middle and late in the set of tapes. This allowed observer drift to be estimated as it took four months to complete the analysis of these tapes.

In this analysis there were a number of tests of statistical significance carried out on different data sets. Following Bakeman & Gottman's recommendation (1986) the alpha level was set by dividing the significance level of .05 by the number of tests carried out.

Bakeman & Gottman (1986) suggest that no analysis of more than two-stage transitions should be attempted in an exploratory study as the number of observations required for more complex analysis would be huge necessitating an equally high level of statistical significance. In order to carry out an analysis of 2-stage transitions

Bakeman & Gottman (1986, p139) propose the following formula to calculate the minimum number of sequences (Ns) which need to be extracted from the data: Ns = 9/P(1-P) where P=1/k*1/k-1. In this instance (with k=4 behaviour codes) 119 two-stage transitions are required for analysis: 872 were obtained. However, more observations than were taken would be necessary for an analysis of 3-stage transitions.

B) The qualitative analysis.

The qualitative analysis was carried out after the quantitative analysis was complete but before the intra-rater recodings had been done. It was developed by the experimenter and second rater watching sessions from a previous experiment. They identified key points in each session which exemplified social interaction in the sense of one individual's behaviour affecting the other's behaviour. This was done by viewing the tapes at normal speed, pausing when such an interaction was observed, noting the approximate time of the event and briefly describing the behaviour and the response. Response categories were initially proposed as Welcomes, Supports, Accepts, Avoids or Rejects.

The raters then viewed independently the two best sessions for each of the 20 pairs: the approximate time of key interactions was noted alongside a description of the exchange. Information was then compared; interactions noted by both raters were recorded, those noted by only one discarded. Interactions which had been observed by both raters but interpreted differently were debated and a negotiated description reached on most occasions; major disagreements were regarded as informative in themselves and were also noted. The distinctions between Welcomes and Supports, and between Avoids and Rejects, were not reliable and were merged. Other aspects of the interactions became relevant for different people. The last part of the qualitative analysis was agreeing a global description of the style of interactions between each pair.

RESULTS

A. THE QUANTITATIVE ANALYSIS

The following questions were asked of the data.

1. Is the coding reliable?
2. Was there a change in the clients' responses from the first to the fifth session?
3. What was the overall rate of the four types of client behaviours?
4. How much did staff talk in these sessions?
5. Was there a pattern of transition from one type of behaviour to the next in the client group or were changes between behaviours all equally likely?
6. What staff behaviour change precedes client behaviour change?
7. What client behaviour change precedes staff behaviour change?

B. THE QUALITATIVE ANALYSIS

The following questions were asked of the information.

1. What were the characteristics of client-keyworker pairs for which the raters agreed few or no interactions?

2. What types of interactions were most commonly observed across all pairs?
3. Was interpersonal distance an important dimension in this analysis?
4. Which pairs seemed to have the most successful and positive sessions and what happened during these?

A. THE QUANTITATIVE ANALYSIS

1. Was there a change between the clients' first and last sessions?

A Wilcoxon signed ranks test was used to compare the amount of positive responding shown by all clients in the first and last sessions: there was no significant difference (Z= -0.93).

Examination of the raw data showed that half of the sample had increased the total amount of positive responding and half had decreased.

Table 1.1: Amount of positive responding in the first and last talk sessions and the clients' S.G.S. scores.

INCREASERS			DECREASERS		
PAIR	1st-5th	MEDIAN	PAIR	1st-5th	MEDIAN
9	12-49	12	10	52-25	12
14	10-66	6	11	36-25	3
15	23-97	15	12	48-21	12
17	21-55	6	13	78-4	15
18	12-107	1	16	4-3	9
21	42-130	9	19	21-0	6
22	25-33	3	20	11-1	6
24	20-45	3	23	96-59	12
25	8-40	9	26	83-65	9
27	13-29	9	29	15-4	6
MEDIANS:		7.5			9

A t-test between the S.G.S. scores for the two groups was not significant.

These results suggested that there was no order effect nor clear reason from a developmental age point of view why some clients responded well early on and others did so later. Three of the four staff who worked with two clients had one client whose positively-coded behaviour increased and one client whose positively-coded behaviour decreased.

The remaining analysis was carried out on the two sessions which staff and experimenter had agreed were the most successful out of the five recorded.

2. Was the coding reliable?

Table 2.1: Inter-rater agreement.

Staff and client codes entered into the agreement matrix as described in chapter 8, second by second.

	CLIENT CODES			STAFF CODES		
Pr	%Ag.	Kappa	L&K	%Ag	Kappa	L&K
13	93%	.89	al.perf	85%	.35	fair
13	57%	.40	fair	90%	.39	fair
20	87%	.64	subst.	93%	.82	al.perf
20	54%	.31	fair	98%	.67	subst
25	31%	.16	slight	97%	.5	moder.
25	56%	.45	moder.	94%	.34	fair

Strength of agreement measured by the Kappa statistic proposed by Landis & Koch (1977): categories are slight, fair, moderate, substantial and almost perfect.

All of these results for the client codes were significant at <.001.

Table 2.2: Intra-rater agreement.

Client and staff codes entered into the agreement matrix as described above.

	CLIENT CODES			STAFF CODES		
Pr	%Ag	Kappa	L&K	%Ag.	Kappa	L&K
9	96%	.89	al.perf	96%	.5	moder.
9	98%	.96	al.perf	91%	.64	subst.
17	98%	.97	al.perf	93%	.56	moder.
17	94%	.87	al.perf	99%	.5	moder.
27	94%	.91	al.perf	98%	.8	subst.
27	88%	.73	subst	99%	.9	al.perf

3. What was the overall rate of the four types of client behaviours in the two best sessions?

Data were derived for each type of behaviour for all 20 clients in their two best sessions. Results are reported as percentages for the whole group and for individuals.

Positive behaviours (described as 1 in following tables):
mean = 32% median = 30%
range for individuals = 0 to 93%.

Negative behaviours (described as 2 in the following tables):
mean = 6% median = 0
range for individuals = 0 to 72%.
8/20 clients showed no negative behaviour in either session.

Stereotyped behaviours (described as 3 in the following tables):
mean = 18% median = 9%
range for individuals = 0 to 66%.
5/20 clients showed no stereotyped behaviour in either session.

Neutral behaviours (described as 4 in the following tables):
mean = 43% median = 44%
range for individuals = 0 to 87%

Uncodable behaviours:
mean= 1%.

Uncodable behaviours were omitted from further analysis.

4. How much did staff talk in these sessions?

mean = 85% median = 91%
range for individuals = 53% to 99%

5. Was there a pattern of transition between one type of behaviour and the next in the client group?

Table 5.1: The analysis of transitions in the clients' behaviour from one state to another, same-same transitions excluded. Expected frequencies generated from Lemon & Chatfield's (1971) formula.

			FOLLOWING		
	1	2	3	4	Tot
P 1	-	12(23)	47(63)	242(218)	301(304)
R 2	13(30)	-	10(12)	36(43)	59(85)
E 3	46(74)	10(11)	-	87(104)	143(189)
C 4	235(190)	39(28)	95(77)	-	369(295)
Tot	294(294)	61(62)	152(152)	365(365)	872

Key: 1 = Positive
2 = Negative
3 = Stereotyped
4 = Neutral

	RAW	CP[2]	UP[3]	Z	PROB
1-2	12	.04	.08	-4.44	<.001 *
1-3	47	.16	.21	-3.57	<.001 *
1-4	242	.80	.72	5.33	<.001 *
2-1	13	.22	.35	-8.125	<.001 *
2-3	10	.17	.14	2.5	.0124
2-4	36	.61	.51	5.88	<.001 *
3-1	46	.32	.39	-4.12	<.001 *
3-2	10	.07	.06	-	
3-4	87	.61	.55	2.61	.009
4-1	235	.64	.64	-	
4-2	39	.11	.09	2.22.	.03
4-3	95	.26	.26	-	

Nine tests of significance were carried out and so the alpha level was set at .0055 (ie .05/9).

The following are all significantly unlikely transitions.
Positive to negative; positive to stereotyped; negative to positive and stereotyped to positive.

The following transitions were found to be significantly more likely.
Positive to neutral and negative to neutral.

6. Client responses to changes in staff behaviour.

This was examined by identifying each change in the staff's behaviour (stopping or starting talking) and recording whether a change occurred in the client's behaviour simultaneously or at lags

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[2] Conditional Probability obtained by dividing the raw score for a particular response following a target behaviour by the total number of responses made following that target (Lemon & Chatfield 1971).

[3] Unconditional probability obtained by dividing the expected frequency of a particular behaviour following the target behaviour by the total number of expected responses following that target (Lemon & Chatfield 1971).

of one, two or three seconds. Six tests of significance were carried out and so the alpha level was set at .008 (ie .05/6).

Table 6.1 Client change simultaneous with staff change (starting or stopping talk combined).

Client change to:	Staff change	CP[1]	UP[2]	Z	PROB.
1	36	.29	.32	-	
2	15	.12	.06	3	.003 *
3	16	.13	.18	-	
4	32	.46	.43	-	

This suggests that clients were most likely to respond negatively when staff changed behaviour.

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[1] Conditional probability calculated as before following Lemon & Chatfield 1971.

[2] Unconditional probability obtained from the mean of each response type in the whole data set.

TABLE 6.2 Client responses to staff change at 1-, 2-, and 3-second lags.

1 SECOND LAG

CLIENT TO:	ST.STOP	ST START	CP	UP	Z	PROB.
1	12		.26	.32	.8	NS
1		26	.41	.32	1.28	NS
2	8		.17	.06	3.14	.0016
2		2	.03	.06		
3	7		.15	.18		
3		13	.2	.18		
4	29		.63	.43	2.86	.0042 *
4		23	.36	.43		
Tots(Ncrit)	46	64				

2 SECOND LAG

CLIENT TO:	ST STOP	ST START	CP	UP	Z	PROB.
1	17		.26	.32		
1		18	.31	.32		
2	6		.09	.06		
2		9	.16	.06	3.33	<.001 *
3	14		.22	.18		
3		9	.16	.18		
4	28		.43	.43		
4		22	.38	.43		
Tots (NCrit)	65	58				

3 SECOND LAG

CLIENT TO:	ST STOP	ST START	CP	UP	Z	PROB.
1	16		.27	.32		
1		16	.23	.32		
2	5		.08	.06		
2		6	.08	.06		
3	8		.14	.18		
3		16	.23	.18		
4	30		.51	.43		
4		33	.46	.43		
Tots (NCrit)	59	71				

This suggests that at one second lag clients respond significantly more often with both negative and neutral behaviour when staff stop talking; at 2 second lag clients respond with negative behaviour when staff start talking and there is no significant association at 3 second lag. This is consistent with the finding in Table 6.1 that clients were significantly more likely to respond negatively simultaneously with staff changing behaviour, stopping and starting talk combined.

7. Staff responses to changes in client behaviour.

This was examined by identifying each change in the client's behaviour and recording whether a change occurred in the staff's behaviour simultaneously or at lags of one, two or three seconds. Thirteen tests of significance were carried out and so the alpha level was set at .004 (ie .05/13).

Table 7.1: Staff change simultaneous with client change.

Client to:	Staff	Raw	CP[1]	UP[2]	Z	PROB.
1	stop	20	.56	.15	6.8	<.001 *
	start	16	.44	.85		
	tot	36				
2	stop	7	.46	.15	3.55	<.001 *
	start	8	.54	.85		
	tot	15				
3	stop	9	.56	.15	5.125	<.001 *
	start	7	.44	.85		
	tot	16				
4	stop	26	.45	.15	6	<.001 *
	start	32	.55	.85		
	tot	58				

These results show that simultaneously with the client changing to any behaviour the staff were most likely to stop talking.

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[1] Conditional probability calculated by dividing the observed frequency by the total amount of that response obtained when staff either start or stop talking.

[2] Unconditional probability from the mean time staff spent talking /not talking.

Table 7.2: Staff responses to changes in client behaviour at 1-, 2- and 3-second lags.

1 SECOND LAG

CLIENT TO:	STAFF	RAW	CP	UP	Z	PROB.
1	STOP	14	.34	.15	3.16	.0016 *
1	START	27	.66	.85		
	T	41				
2	STOP	3	.25	.15	NS	
2	START	9	.75	.85		
	T	12				
3	STOP	7	.26	.15	NS	
3	START	20	.74	.85		
	T	27				
4	STOP	7	.15	.15		
4	START	39	.85	.85		
	T	46				

2 SECOND LAG

CLIENT TO:	STAFF	RAW	CP	UP	Z	PROB.
1	STOP	23	.59	.15	8.3	<.001 *
1	START	16	.41	.85		
	T	39				
2	STOP	3	.25	.15		
2	START	9	.75	.85		
	T	12				
3	STOP	6	.27	.15		
3	START	16	.73	.85		
	T	22				
4	STOP	29	.58	.15	8.6	<.001 *
4	START	21	.42	.85		
	T	50				

3 SECOND LAG

CLIENT TO:	STAFF	RAW	CP	UP	Z	PROB.
1	STOP	23	.52	.15	6.9	<.001 *
1	START	21	.48	.85		
	T	44				
2	STOP	5	.5	.15	3.18	<.001 *
2	START	5	.5	.85		
	T	10				
3	STOP	12	.5	.15	5	<.001 *
3	START	12	.5	.85		
	T	24				
4	STOP	24	.53	.15	7.6	<.001 *
4	START	21	.47	.85		
	T	45				

These results show that staff are significantly more likely to respond to all client behaviours at the 3-second lag. Viewed alongside the result for simultaneous reactions it can be seen that the response to client change made by staff in both situations is to stop talking. At earlier lags the picture is more mixed. Staff were more likely to stop talking one second and two seconds after the client changed to positive and they were more likely to stop talking two seconds after the client changed to neutral; staff did not respond to other changes.

B. THE QUALITATIVE ANALYSIS

A qualitative description of each session for each client-keyworker pair is given in Appendix E from which the following is drawn.

1. What were the characteristics of client-keyworker pairs for which the raters agreed few or no interactions?

Raters could not agree on key interactive episodes for pairs 11 and

17. For pair 11 the style of the sessions was decribed as "restricted"; the client had a median developmental age of 3 months but was ambulant with no additional disabilities. The sessions were characterised as "lacklustre" for pair 17; the client had a median developmental age of 6 months and was severely physically disabled.

There were 2 pairs who had only two interactions agreed across their sessions: these were pairs 10 and 16. The sessions between pair 10 were characterised as "mutual co-existence", showing little evidence of social exchange between the people. Client 10 had a median developmental age of 12 months and was ambulant with no sensory impairments. The keyworker in pair 10 gave mixed messages with face and voice such as mock anger which raters found difficult to interpret. The sessions between pair 16 were affected by the keyworker seeming to physically overwhelm the client whose behaviour suggested rejection and avoidance of such intimate contact. Client 16 had a median developmental age of 9 months, was physically disabled but had control of her head and arms.

The clients in this section had median developmental ages of 3,6,12 and 9 months respectively.

2. What types of interaction were most commonly agreed across all pairs?

The notes suggest that the most common exchange was for the client to initiate contact by touching the keyworker, usually their hand, to which the keyworker responded with a look or smile or comment. The second most commonly noted exchange was for the keyworker to ask for the client's attention and get it. Third was for the keyworker to ask a question to which the client responded:

this exchange usually seemed to indicate that the client knew some sort of response was required rather than that their response was informative or appropriate. The fourth most commonly noted exchange was for the client to smile and the keyworker to smile in response. Finally, the fifth most commonly noted exchange was for the client to back away and the keyworker to lean further forwards in response.

3. Was interpersonal distance an important dimension in this analysis?

One keyworker was thought to be too far away from the client, five were thought to be too close. The client leaning back or away and the keyworker leaning forward in response was the fifth most commonly observed exchange, suggesting that clients quite often felt crowded. However, some of the interactions which were most positive occurred at very close proximity, such as those described below between pair 21. The results suggest that interpersonal distance is an important dimension to consider when trying to interact with profoundly intellectually disabled adults.

4. Which pairs seemed to have the most successful and positive sessions and what happened during them?

The first session of pair 13 was facilitated by the visit of a baby to the unit, an event which this client particularly enjoyed. The session contained much positive social initiative from the client such as looking, smiling, clapping and taking the keyworker's hand all of which the latter responded to. There was also vocalisation and vocal turn-taking. Client 13 had a median developmental age of 15 months and no additional disabilities.

The second session of pair 15 included an extended interaction about swimming. The keyworker was trying to indicate swimming by gesture: each time his hands came near the client she tentatively put hers onto his and then withdrew them as he pulled round to finish the stroke. It was not clear what the client understood from this interaction but her extended engagement with the keyworker during the exchange was distinct from the rest of their sessions. This client had a median developmental age of 15 months and no additional disabilities.

The second session between pair 18 had no distinct social exchanges but was characterised by a very positive style throughout. It seemed as if a slight difference in the keyworker's position, so that she was facing the client rather than slightly to one side, had facilitated sustained looking and smiling from the client. This client was profoundly physically disabled with a median developmental age of 1 month.

Both of the sessions held between pair 21 had teasing, laughter and hugging games which were initiated by the client and which involved an apparently familiar collusion between the pair so that the keyworker made mock objections but did not try over-hard to extract herself. The client seemed very responsive to the keyworker, whose speech had an animated and sensual quality to it and the pair maintained an intimate social distance. Client 21 had a median developmental age of 9 months and was non-ambulant.

The median developmental ages of these clients were 15, 15, 1 and 9 months respectively.

DISCUSSION

The inter-rater agreements for the client codings show more variation than in the previous studies and the results for one client (25) are fairly low. The second rater had stated that he found it difficult to interpret this person's behaviour during coding. The difficulty seemed to be two-fold: firstly, that the client moved and changed behaviour very quickly and, second, that the client showed a range of stereotyped behaviours which the experimenter and staff member recognised but which the rater did not. Some of the movements were fleeting examples of stereotyped behaviours familiar to experienced staff, such as a hand-flick at the corner of his eye, which no longer had the repetitive quality usually associated with stereotyped movements and so the rater saw them differently. The experimenter and rater had equal difficulty agreeing on this client's qualitative analysis.

Observer drift has been noted when analysis takes more than a month or two (Bakeman & Gottman, 1986); periodic checks and retraining against an agreed standard are recommended to avoid this problem. As individual coding schemes were prepared for each client it was not clear how re-training could be done. Variation in inter-rater agreement figures suggests that disagreement on the classification of particular behaviours rather than wholesale drift was affecting these results. The intra-rater agreements were 88% or better for both client and staff codes. They show little difference between subjects from the beginning, middle or end of the data set and do not suggest that observer drift was a problem here.

Inter-rater agreement for the analysis of presence or absence of keyworker talking seemed acceptable from inspection of the agreement percentages but not if Cohen's Kappa is the indicator. Doubts have been expressed already about the utility of Kappa in certain situations. Where there is a two by two matrix it seems that the Kappa figure often differs considerably from the agreement percentage. Kappa appears to be adversely affected by a small number of cells in the analysis when the correction for guessing becomes extremely high.

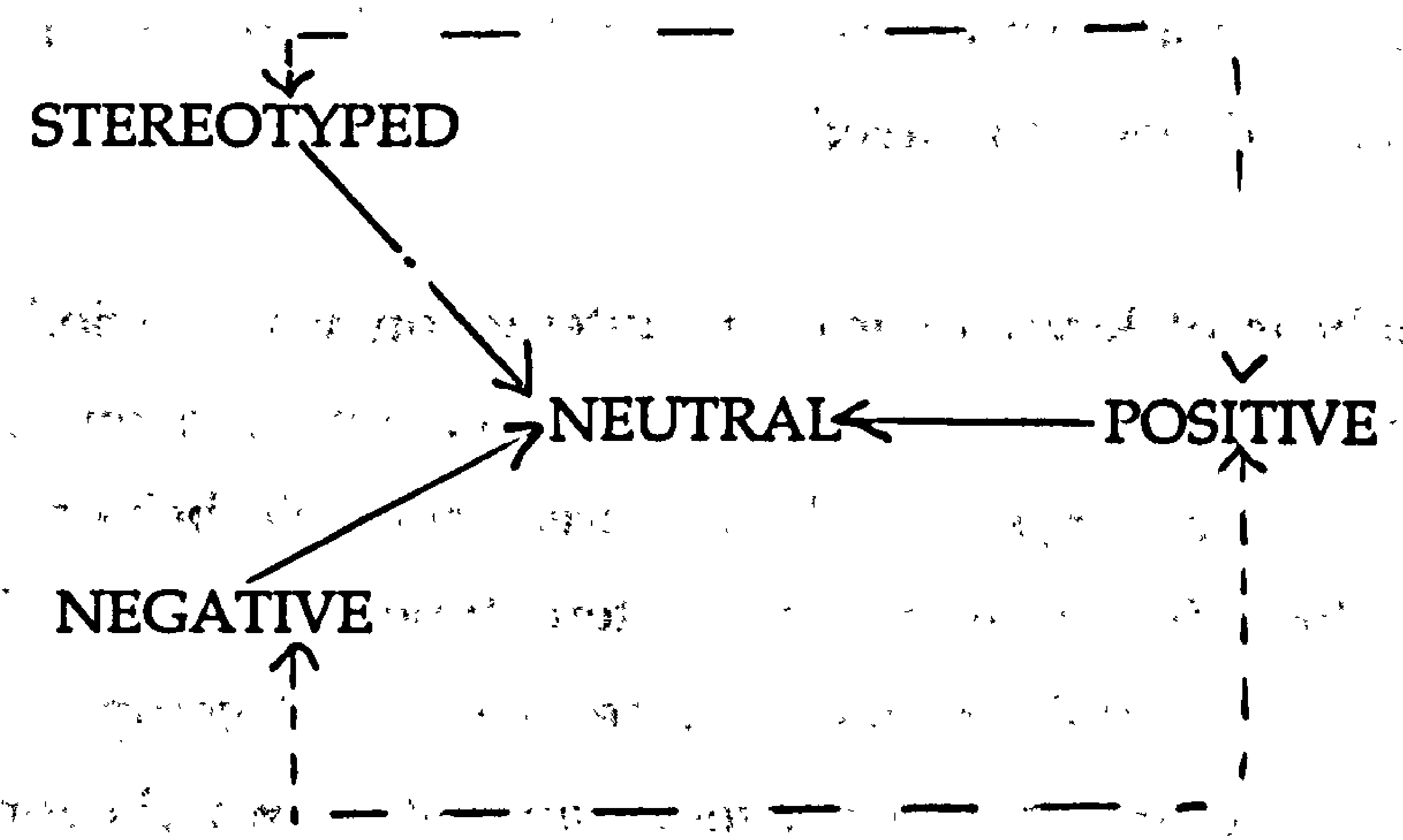
Intra-rater agreement was high for all of the client codings. For the staff codes it was equally high if agreement percentages are accepted and again the figures seem questionable for Kappa. The translation of a 99% agreement to a Kappa of .5, categorised as a'moderate' level of agreement, seems inappropriate.

The high levels of intra-rater agreement and the reasonable levels of agreement for most of the clients suggest that the analysis of data obtained from observation is fairly well grounded. However, the variability in agreement between raters underlines how difficult it can be to interpret the behaviour of profoundly disabled adults.

The amount of time spent by these clients in each of the four types of behaviour gives a rough guide to carers about what they may expect in relatively ideal conditions. Clients were most likely to display neutral behaviour, which occurred nearly half of the time. They were likely to behave positively about a third of the time, displayed stereotyped behaviour between a fifth and a tenth of the time and displayed relatively little negative behaviour.

Sequential analysis of change in client behaviour provided insight into the relationship between the different types of behaviour in this coding scheme. Transitional probabilities suggest that a model which revolves around a dimension of internally and externally focussed attention or arousal could be useful. The basis of this proposed model is that the client may be focussing attention inward while showing stereotyped behaviour and making themselves relatively "unavailable" to external stimulation. Their focus of attention could also be inward if they were uncomfortable or trying to maintain control of their physiological state. Their positive behaviours are more likely to have an outward focus. Such an approach combines some of the observations made by Baumeister (1978) about the nature of stereotyped behaviour with those of Als (1982) concerning interacting with a disabled infant.

It is suggested that the client cannot move directly from an inwardly-focussed state to one of accepting or responding to social stimulation. The client in a stereotyped state can only take part in social interaction by passing through an intermediate emotional state which appears neutral or passive to observers. The client in a negative state also needs to settle by passing through this neutral or passive phase before they can interact with others. The following model could describe the movement between states.



Evidence for this model comes from Table 5.1. Transitions in both directions betweeen negative and positive and between stereotyped and positive were all significantly unlikely (marked with a dotted line). The transitions from negative to neutral and from positive to neutral were significantly likely (marked with a solid line). The transition from stereotyped to neutral was likely to occur but the probability of .009 escaped statistical significance due to the large number of tests carried out. These last three results were in only one direction, as would be expected if all behaviours tend to lead to neutral but are equally likely to go from neutral to any of the other three behaviours.

None of this information illuminates the relationship between negative and stereotyped behaviour, which requires further investigation. One reason for this relationship being unclear is the low rate of negative responses obtained by collecting data in a relatively ideal situation. The inclusion of self-injurious behaviour in the negative rather than the stereotyped category may also have confounded these results. Self-injury was classified as negative because it often does not have a repetitive, stereotyped quality and because clients sometimes appear to use it to communicate objections. On the other hand, most analyses of self-injury describe it as a special case of stereotyped behaviour (for example, Murphy & Wilson, 1985) and perhaps the relationship between negative and stereotyped behaviours in this study would have been clearer if that distinction had been followed.

Sequential analysis of keyworker-client interaction was carried out to examine the direction and type of influence. One reason for no strong patterns emerging is that there were 4 possible behaviour states for the client (positive, negative, stereotyped and neutral) but only two for the staff (talk/no talk). The analysis of complex interactions such as proximity or level of animation was beyond the limitations of these films. The focus of filming had been on the client and many staff had chosen to position themselves so that they had their backs to the cameras. Natural versus laboratory-based data collection has been debated. It was felt at the time of filming that the staff should be able to control the sessions even if this meant losing some information about their input.

The analysis of client response to staff either starting or stopping talking was carried out simultaneously (Table 6.1) and at various lags (Table 6.2). Results suggest that the client is most likely to respond within two seconds and that waiting longer is unnecessary. Significant client responses were a change to negative behaviour in three instances and a change to neutral in one. It is possible that any change in the staff behaviour disrupted the client's existing state; the results are difficult to interpret but not inconsistent with the proposition that state or level of arousal is a central issue in understanding social interaction in profoundly disabled adults.

One reason for carrying out this analysis was to see if it was important to offer the person turns by stopping talking as turn-taking has been an important feature of research into mother-infant interactions. It was possible that positive behaviours such as looking and smiling would onset a few seconds after the person had been effectively offered a turn by the staff stopping talking but there was no evidence to support this.

The analysis of staff response to clients showed greater sensitivity. Staff were significantly likely to respond to any change in the client's behaviour in the same second and also three seconds afterwards (Tables 7.1 & 7.2). At one and two second lags they were significantly likely to respond at the onset of a positive client behaviour. These results show that staff were alert to changes in the clients' behaviour and their response of stopping talking could be seen as offering the client a turn which was not taken up.

The qualitative analysis described interactive exchanges between keyworker and staff. Therefore only a small part of the three minute sessions is described as the two interactants spent much of their sessions not so engaged, although they may have been building up to interact or settling after an interaction. This analysis described successful and less successful sessions, their style and the proximity between interactants. Neither developmental age nor presence of sensory impairments predicted which clients would be involved in successful as opposed to unsuccessful interactions.

The raters felt that future qualitative analysis should include a category of Prevents, as the keyworker frequently intervened to stop an inappropriate or self-injurious behaviour from the client. This analysis was biassed towards the exchange of touch or of vocalisation; these were most easily agreed as being interactions although raters would necessarily see them as being most important.

The qualitative analysis makes a contribution at the descriptive level. One major recommendation came from it. That is, that staff should try to vary their proximity and position particularly with physically disabled clients. Some clients enjoyed their keyworker being very close but a quarter seemed to be giving cues that they felt crowded.

CONCLUSIONS

This study described interactions between staff and profoundly intellectually disabled adults under ideal conditions. A lag analysis of the interactions between staff and client did not find support for the importance of offering turns to clients. There was relatively little evidence of clients being sensitive to staff: what there was suggested that clients were disrupted by changes in staff behaviour since usually they behaved negatively when they did respond. Responses were most likely within the first two seconds. Staff were sensitive to all types of client changes but were particularly responsive to positive behaviour.

Results from the quantitative analysis of client behaviour were summarised into a descriptive model of transitions in the client's state. Further development will require examination of the relationship between negative and stereotyped behaviours. This approach to conceptualising the needs of profoundly disabled people was recently discussed by Sternberg & Richards (1989). Investigation of arousal may prove to be a more useful basis for generating hypotheses about profound intellectual disability than have alternative models.

The qualitative analysis provided information about interactions and style which may be useful to staff trying to develop a relationship with somebody profoundly disabled. Results showed that proximity was an important issue in the interactions between clients and staff although the only recommendation is that staff vary their position and judge the outcome with that particular individual.

Developmental age was not found to be predictive of client behaviour in either analysis.

PART IV

CHAPTER 11: DISCUSSION AND CONCLUSIONS

The socio-emotional life of adults with intellectual disability was explored in this project. Cognitive processes have been the focus of many recent investigations (eg, Brooks et al 1984; Tymchuk et al, 1988) but this research considered the role of affect. Methodological aspects of the studies are discussed first followed by consideration of their contents as a whole.

The emphasis placed on conceptual issues, both for understanding relationships and for understanding intellectual disability itself, reflects a change discussed by a number of psychologists. The important issue appears to be the generation of theoretical perspectives and problems if science is to develop. It was suggested in chapter 9 that such revision should refer to the philosophy of science concerning model and theory construction. Baumeister's (1987) paper on concepts and dilemmas concluded that the study of intellectual disability needs fundamental conceptual revision.

The samples used in these studies were neither representative of adults with intellectual disability as a whole nor of the two groups on which the investigation focussed, adults with mild or moderate disability and adults with profound disability. The studies were exploratory and concerned issues which some individuals found challenging. A number of people refused to take part in the investigation of friendship in verbally skilled disabled adults, a number of staff declined to be involved in the study of staff-client interactions and a few next-of-kin did not assent to their relative taking part.

Both sets of studies investigated people in more than one setting, permitting generalization of the results beyond specific environments. The study with mildly disabled people was carried out with a small proportion of the group as a whole; the results provide some signposts for future research and intervention. The study with profoundly disabled people involved a quarter of the estimated total population in at least one of its stages, working with staff and clients from three of the six units providing services for this group in the district. The results of this study may have greater generality.

Valsiner's (1987) ideas about psychological research were summarised in Chapter 1. He described four perpectives on research with human subjects: the intra-individual, the inter-individual, the individual-ecological and the individual-socioecological. He also proposed five guidelines about research design; these are used below as a yardstick for considering the results of these studies.

a) Developing processes are more interesting than static entities.

The study of friendship used a modified repertory grid which asked questions about the subjects' view of their peers and themselves. While this was an investigation of relatively static entities the results on the link between self-rating and friendship could be employed in future studies of the process of change during friendship formation.

The interaction studies were more concerned with developing processes. They investigated client responses to different strategies used by keyworkers, transitions in the client's behaviour during interaction and the responsiveness of client to keyworker and keyworker to client. However, a truly developing study would be a one employing a longitudinal design.

b) Research should be relativistic.

Valsiner was suggesting here that research should make as explicit as it can the experimenter's frame of reference, cultural axioms and core theoretical concepts derived from them, given that full awareness of cultural influences is not possible. This was also proposed by Harre in his discussion of the interaction between the experimenter's analytic and explanatory schema.

The multiple influences affecting disabled people's experience of friendship were reviewed in Chapters 1 and 2. Allan's (1989) discussion of the sociological constraints of power and resources is linked with the social anthropologists' perspective on disabled people coping in societies which devalue disability. Surveys suggest that recent changes to these constraints have not changed the relationships experienced by disabled people. This study took an intra-individual perspective not because it was assumed that internal factors were the only relevant variables in understanding friendship but because it was an aspect which had been relatively unexplored.

The data obtained were constructed through negotiation between the author and each participant: they are relativistic in that each subject's personal view of friendship was the origin of half the data base. A definition of friendship was provided so that the theoretical basis of the investigation was made explicit.

The studies of profoundly disabled adults drew on ideas from child development, on theories of personality in non-disabled adults and on reports of interventions from practitioners. These ideas were developed into a study taking Valsiner's socio-ecological perspective, by which he meant studying the way that an incompetent individual copes with their environment through interaction with a competent other. Social constructionism formed the theoretical base of these studies although perspectives from other work were also combined with observational information about strategies employed by experienced staff. This series of studies were open-ended, each affected by the results of earlier stages. They seem to fit Valsiner's criterion of good practice with regard to relativistic research.

c) The person-environment separation is a false dichotomy since they are interdependent.

The friendship study was carried out in day centres and asked questions about peoples' relationships with peers attending them as this is the daytime environment which most intellectually disabled adults use. Many investigations of relationships have looked at people's social contacts in the wider community but this study agreed with Flynn's (1989) view: "It appears misguided, however, to hope that friendships can develop with non-mentally handicapped people and to aspire to this for everybody....It is to be expected that people who have spent vast periods of their lives associating with people with a mental handicap will form friendships with them."(p72).

The investigations of interaction with profoundly disabled people were rooted in interdependence between client and keyworker.

d) Inter-individual variability is not a source of error but an indicator of adaptability.

This is particularly relevant to the investigation of intellectual disability as individual variability is one of the key characteristics of this condition.

The use of elicited constructs in Chapter 3, the use of an own-control design in Chapters 7 and 8 and the use of individual coding schemes for Chapters 7, 8 and 9 give a valued place to individual variation. The qualitative descriptions of interactions between staff-client pairs given in Appendix 9.1 provide information about the range of activities observed.

e) Structurally holistic research is preferable to additive elementarism.

This is a difficult maxim to follow, as researchers risk creating myriad theories based on scant evidence. Nevertheless, theoretical development has been argued to be essential to the growth of psychology.

The system from which the friendship study was derived has been discussed from a number of perspectives and the results should be viewed as complementary to them. However, this research design could be criticised as belonging to additive elementarism. It was an exploratory study and future development should combine individual views with environmental measures so that complexities within the system are revealed.

The studies of interaction with profoundly disabled adults were carried out in coordination with theoretical issues as conceptual development was one of the project aims. The utility of taking a theoretical position was partly illustrated by noting its boundaries. It was suggested that under some circumstances a multiply disabled person's physical limitations overwhelmed a socially constructed perspective on their behaviour and required investigation from a different theoretical perspective which was at an intra-individual level.

A descriptive model of transitions in the behaviour of profoundly disabled adults was proposed, alongside information about the effects of various staff interaction strategies. As Kelly and Valsiner recommend, the information was used to arrive at a new construction of events.

While Valsiner's maxims provide a framework for assessing method and design issues there are two additional points raised by Reason & Rowan (1981) and by Marshall & Rossman (1989) which merit discussion. The first is the relative contribution of the quantitative and qualitative aspects of the studies and the second is consideration of this research from the participants' perspective.

In the friendship study the significant results all came from the quantitative analysis. A number of different ideas were investigated using these methods which are easily translated into recommendations for future research and practice.

The quality of people's relationships was explored by comparing the types of constructs used by people in Groups 1 and 2 but no difference was found. During the study descriptions of friendship were given by 36 people from whom constructs were elicited. Some people with limited verbal comprehension on the BPVS expressed sophisticated ideas about the people around them: for example, one person noted that her room-mate in the home was the sort of person who had to be first everywhere. Rich material about the views intellectually disabled people hold about their relationships was lost from this study. Perhaps new techniques such as discourse analysis (Potter & Wetherall, 1987; Antaki, 1988) will enable future research to capture that richness.

The studies of interaction between staff and profoundly disabled adults were primarily quantitative. Assessment of the results depends upon the validity of the coding schemes. The results obtained provide clear information to people about strategies to try when interacting with somebody, about their likely effects and about the types of interactions which occur between staff and clients in Talk sessions. The disadvantages of the quantitative approach are that more global, holistic views of the interaction are missed and that some aspects were omitted simply because of coding difficulties.

The qualitative analysis of the last study was designed to complement information obtained from the sequential analysis. Its contribution can be compared to the utility of a subjective description of events from one person's point of view. In this study an attempt at reliability was made by only recording events which two raters independently noted as key exchanges and by subsequently negotiating a description of the interactive style. The resulting notes in Appendix 9.1 give a useful summary of the range of interactions observed but do not provide the sort of insightful description reported by Als (1982). However, Als was reporting the interactions of only three pairs; such detail on twenty pairs would have been unwieldy, larger samples requiring some level of analysis or abstraction. Summarising qualitative data was discussed by Marshall & Rossman (1989) and is a difficulty sometimes associated with this technique.

The view that quantitative data is scientific while qualitative data is humanistic is supported by these results. The qualitative studies were not strong enough to stand alone but provided humanistic data to flesh out the rather skeletal information obtained from quantitative analysis.

The final methodological issue is how the research affected the participants. People who took part in the friendship study were invited to a meeting in their day centre to hear about the research results; for some the meeting was held more than a year after the project had finished. This did not seem to be a meaningful exercise for the majority of the group as the idea of research was difficult to communicate to them. Some individuals used the meeting to renew our acquaintance and recalled the interviews with pleasure while others had forgotten them. Nobody seemed to have been upset by the project; apart from the people who enjoyed discussing their relationships with an interested stranger, positive outcomes for the participants are most likely to arise out of feedback given to day centre staff.

The interaction study had more positive reports. Managers of the three participating units all volunteered the comment that their staff had enjoyed taking part and had found discussion of their interactions while viewing the final sessions helpful. Staff in one of the units felt so confident about using videotape to study their interactions that they were dominating the camera intended for use in the whole centre. Feedback sessions to staff in each of the units were generally positive, some people asking to take part in the next stage of the research and stating that their relationship with the client had improved as a result of the project. It is assumed that clients benefitted from the enthusiasm and interest of staff.

Key points about the content of each investigation were made in the relevant discussion sections. A merger of theory, previous research and the results from these studies suggests the following formulations.

Friendship is a multifaceted phenomenon which can be studied from Valsiner's four perspectives; intellectually disabled adults seem to experience problems at all levels. Power and resources need to be increased to facilitate people's access to situations conducive to friendship formation; societal change concerning disability needs to occur to help disabled people to value themselves and one another; and the social organization of services for people with disabilities also needs to change so that they do not inhibit friendship.

On an individual level people need help to increase the amount of social contact they experience since this is an area where people learn from experience, their knowledge of self and others being socially constructed. Social skills which have been suggested to be important are self-disclosure, empathy and coping with negative comments such as criticism. However, these social skills should form only one part of a multimodal intervention which would also offer people the opportunity to discuss self and disability and which would apply strategies found to be useful to non-disabled lonely people.

An ecological perspective on interactions between profoundly disabled clients and keyworkers suggests that the person's needs for freedom from chaos and for safety must be met. Profoundly disabled adults are also likely to respond well to social environments which provide predictable experiences. Increasing the amount of social contact experienced by profoundly disabled people should be a goal of services. Buber's ideas may help to make the experience meaningful for carers.

Positive interactions between profoundly disabled clients and familiar keyworkers are not easily achieved; in relatively ideal conditions clients responded Positively about a third of the time during three minute Talk sessions. These and sessions using Social Routines were the most likely to result in increased Positive behaviour. The qualitative analysis suggested that proximity during interaction was an important dimension for clients.

The strategy Contingent Responding was most likely to result in increases in Stereotyped behaviour when used without any accompanying stimuli. No quantitative evidence of turn-taking was found although it was observed and described between one pair in the qualitative analysis. Turn-taking has been a key issue in interaction studies with other groups and was described by Bruner (1975) as part of the development of language and communication. Its absence may be due to the very limited measures of staff behaviour taken or it may only occur with some clients. Perhaps the few clients who reacted positively when staff responded contingently would also be able to engage in turn-taking.

The model of child development was challenged as an explanation of profound disability since developmental age did not discriminate between subjects in this study. Ideas based on understanding people's state or level of arousal seem a more promising basis for a model. Control of physiology and internal rhythms may be a component of the alert state necessary for social interaction to occur.

Arousal may be the dimension underlying transitions between behaviour types found in this investigation, which showed that clients use Neutral as a transitional state between Positive and Negative and between Positive and Stereotyped. Although Stereotyped behaviour increased under the Contingent Responding strategy it could not be distinguished from Negative behaviour on the transitional analysis; the relationship between these two types of responses requires further investigation.

The role of experience in profound intellectual disability has been missed from these discussions. It is the clearest distinction between children and adults and should be afforded a place in models of the condition.

10.2 DIRECTIONS FOR FUTURE RESEARCH

Future research into friendship between adults with mild and moderate disabilities should develop understanding of the relationship between self, including self as a disabled person, and others. Social constructionism may provide a suitable conceptual framework for such a study.

The development/difference debate could be applied to mildly disabled adults by investigating whether either socio-emotional or mental age predict friendship formation.

This study has investigated friendship at the intra-individual level while many others have examined it from an ecological perspective. The most important future development would be to combine these perspectives in an overall investigation which related individual reports to environmental measures such as opportunities for decision-making and availability of peer support.

Future directions for research into interactions between staff and profoundly disabled clients could investigate the role of keyworker factors by filming the same keyworker with five clients known to them. Such a design could simultaneously test whether any other measures of the individual, such as level of alertness or arousal, predicted their responses.

10.3 CONCLUSIONS

CONCEPTUAL

The argument that new knowledge requires both empirical and conceptual contributions has been developed throughout this work. The studies of interactions and relationships reported have been rooted in social psychology. The study of self-report from mildly disabled people shows ways in which they are both similar and different from linely non-disabled people and underlined the salience of their concept of disability. The stuides of interaction in profoundly disabled people have been rooted in social constructionism in that they were studies of the individual with their keyworker and the keyworker's interpretation of the individual's behaviour formed much of the coding scheme.

The discussion of conceptual and methodological issues relevant to the relationships of people with intellectual disability is itself a contribution as hitherto these issues had not been addressed. The conceptual outcomes from the study with mildly disabled people were as follows: that social comparison theory was not operating but that there were consistent effects associated with self-concept, and that there were limitations to using quantitative techniques to investigate their social world which new qualitative approaches may overcome.

The conceptual contribution from the study with profoundly disabled people was to 'refocus' attention on the interaction between people rather than continuing to locate behaviour solely within the client. It is suggested that we can only know the client through their socially constructed interactions with others because of their dependency. This is not to deny the primacy of some individual factors, such as profound physical disability, in some areas of this group's lives.

Results from the study of profoundly disabled adults suggest that developmental age does not distinguish between members of this group. Results support the suggestion that an individual's level of state or arousal is fundamental to our understanding of profound disability. A descriptive model of the clients' transitions between behaviour states based on a dimension of inner-directed and outer-directed attention or arousal was proposed as a contribution to conceptual evolution.

METHODOLOGICAL

The modified repertory grid provided a way of structuring interviews with people so that their own constructs and those generated by the experimenter could be used. Adults with verbal comprehension over about three years were able to respond reliably to the questions.

A method was devised to carry out quantitative research with profoundly disabled adults using own-control techniques and individually-designed coding schemes which yielded significant results: it will be useful for addressing different questions in the future.

The use of Kappa to measure inter-observer agreement for the profound data was questioned on two counts. Firstly, as Uebersax (1988) noted, there is no reason to assume that observers are guessing when they disagree: reliability calculations on this project supported his contention that observer disagreements were caused by different interpretations of the coding scheme rather than by guessing. Secondly, Kappa produced results which are unacceptably low when there were few cells in the agreement matrix.

Qualitative analyses of these studies provided descriptions of types of constructs of friendship in the first study and descriptions of interactions in the last. These descriptions make a useful contribution by fleshing out quantitative data in exploratory studies which aim to open the topics for further investigation.

PRACTICAL

Results of the investigation of people who had and did not have a peer-group friend suggest the following conclusions.

1.People who had a peer-group friend were more likely to rate themselves as non-disabled and so practitioners should approach insight-based counselling with great caution; perceiving themselves as disabled may be unhelpful to some individuals.

2. Self-disclosure was suggested to be a salient dimension in friendship formation with this group, as with non-disabled people: this may be a useful focus for social skills development in some clients.

3. People without a peer-group friend were similar to non-disabled lonely people and so it is possible that interventions developed for the former can be of assistance to the latter.

Exploration of interactions between adults with profound disabilities and their keyworkers suggest the following conclusions.

1. Sessions lasting about three minutes were comfortable for both parties; clients were likely to respond to staff change within two seconds but staff responded to all types of client change simultaneously and up to three seconds later.

2. Five strategies used by staff were identified and linked to existing literature on interactions with other groups. An evaluation of the effects of these strategies showed that two were associated with increases in positive client behaviour, talk and social routines.

3.The strategy Contingent Responding was not found to result in increased positive responding with this group when used without an accompanying stimulus. Contingent Responding may be effective when combined with active stimulation: investigation of the latter may be more fruitful.

4.The analysis of transitions between the types of responses showed that Neutral behaviour occupies a central, junction position between the other three responses. This suggests that a client behaving in an apparently neutral and passive manner may be passing through an essential state.

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APPENDIX A: TABLE OF CLIENT PARTICIPATION IN VARIOUS STAGES OF THE STUDIES.

PR	SET	1P	2ST	3C.R	4T	REL.S
1	A	Y	N	N	N	N
2	A	Yi	N	N	N	N
3	A	Ya	N	N	N	N
4	A	Yii	N	N	N	N
5	A	Ya	Y	N	N	SR.STRAT
6	A	N	Yiii	N	N	N
7	B	N	Y	N	N	SR.STRAT
8	B	N	Yb	N	N	N
9	A	Yii	N	Y	Y	SR.TALK
10	C	N	N	Y	Y	SR.CONT.R
11	C	N	N	Y	Y	N
12	C	N	N	Yc	Yc	N
13	C	N	N	Yc	Yc	DR3&4
14	C	N	N	Y	Y	N
15	C	N	N	Y	Y	DR.CONT.R
16	C	N	N	Y	Y	SR.CONT.R
17	A	N	N	Yi	Yi	SR.TALK
18	A	Y	Y	N	Y	DR.STRAT
19	A	N	N	Y	Y	DR.CONT.R
20	A	N	N	Yiii	Yiii	DR.TALK
21	A	Y	Y	N	Y	DR.STRAT
22	A	Y	Y	N	Y	N
23	B	N	N	Yb	Yb	SR.CONT.R
24	B	N	N	Yb	Yb	N
25	B	N	N	Yd	Yd	DR.TALK
26	B	N	Yd	N	Yd	SR.STRAT
27	B	N	N	Ye	Ye	SR.TALK
28	B	N	Ye	N	N	DR.STRAT
29	B	N	N	Ye	Ye	N

3 clients were filmed with more than worker (marked by i,ii,& iii) so a total of 26 adults with profound developmental disabilities took part. 10 were from setting A, 9 from setting B and 7 from setting C. There were 15 women and 11 men.

5 members of staff worked with more than one client (identified by a,b,c,d, & e) so a total of 21 staff took part. These were 16 women and 5 men.

The column 'Reliabilities' described which clients had either an inter-rater reliability check (here as DR, different rater) or an intra-rater reliability check (here as SR, same rater).

APPENDIX B: CLIENT CHARACTERISTICS ON THE SCHEDULE OF GROWING SKILLS (S.G.S.).

No	res	age	PP	AP	L	M	V	H/L	S&L	Int	SC	Med
1	I	32	C	C	18	12	6	9	6	9	18	9
2	Full details appear in listing for client 17.											
3	I	39	C	C	18	3	0	9	9	6	24	7
4.	Full details appear in listing for client 9.											
5	I	32	6	C	15	3	1	6	3	6	0	4.5
6.	Full details appear as client 20.											
7	FH	26	3	0	0	6	6	6	6	3	0	3
8	FH	17	1	0	0	3	1	3	0	3	0	1
9	I	25	C	C	9	12	12	12	9	15	18	12
10	FH	24	C	C	24	12	9	9	1	15	18	12
11	FH	38	C	C	24	1	3	9	3	3	24	3
12	I	26	C	C	18	9	12	12	9	15	12	12
13	FH	22	C	C	30	12	15	12	15	24	24	15
14	I	18	6	6	9	6	6	9	6	12	18	6
15	I	19	C	C	24	15	15	24	6	12	30	15
16	I	21	1	6	9	9	9	9	3	3	15	9
17	I	28	6	1	9	6	3	9	3	9	6	6
18	I	25	0	0	0	1	3	6	1	3	0	1
19	I	26	6	6	9	3	0	9	6	6	6	6
20	I	21	C	C	15	6	0	6	6	6	12	6
21	I	34	6	7	12	9	9	9	6	12	15	9
22	I	23	3	0	0	3	12	6	3	3	0	3
23	I	19	C	C	18	6	12	12	6	6	1	12
24	SGH	37	C	C	30	3	3	0	3	6	18	3
25	FH	16	C	C	24	6	6	12	6	9	15	9
26	FH	26	6	7	12	9	12	12	3	9	18	9
27	I	21	C	9	9	9	9	9	6	12	12	9
28	FH	18	6	C	15	1	0	6	0	3	6	4.5
29	FH	20	C	C	24	6	6	3	6	3	30	6

Key for residence: SGH= small group home (>6 people)
FH= family home
I = institution: hospital or voluntary home for more than 20 people.

Key for the SGS: Positive Posture, Active Posture, Locomotor, Mobility, Vision, Hearing & Language, Speech & Language, Interactive, Self-Care. The Median score excluded PP & AP if the person scored at the ceiling level as those two scales stopped before the others.

The S.G.S. was adapted for use with this population by scoring each item individually without assuming that attainment of a higher level skill guaranteed earlier skills were mastered. The items requiring ventral suspension were not done: these were credited unless the client could

TEXT BOUND INTO

THE SPINE

not support their head when sitting.

NFER NELSON

THE SCHEDULE OF GROWING SKILLS

Developmental Screening Procedure: PROFIL

To:

Re. case no:

Signature of examiner

Title

b) Referral to:

Comments:

MONTHS

Skill areas:	Passive Posture	Active Posture	Locomotor	Manipulative	Visual	Hearing & Language	Speech & Language	Interactive Social	Self-care Social	
60 mths			20 19 18	28 27 26	21 20	21 20	22 21	24 23	23 22 21	60 m
48 mths			17 16 15	25 24 23	19 18	19 18	20 19 18	22 21 20	20 19 18	48 m
36 mths			14 13	22 21 20	17	17 16	17 16	19 18	17 16	36 m
30 mths			12 11	19 18 17	16	15 14 13	15 14	17 16	15 14	30 m
24 mths			10 9	16 15 14	15	12 11	13 12	15 14	13 12 11	24 m
18 mths			8 7	13 12	14	10 9	11 10	13 12	10 9 8	18 m
15 mths			6 5	11 10	13 12		9 8	11 10	7 6	15 m
12 mths		12 11	4 3	9 8	11 10	8 7	7 6	9 8	5 4	12 m
9 mths		10 9	2 1	7 6	9 8	6 5	5 4	7 6	3 2	9 m
7 mths		8 7								7 m
6 mths	9 8 7	6 5 4		5 4	7 6	4 3	3	5 4	1	6 m
3 mths	6 5 4	3		3 2	5 4	2	2	3 2		3 m
1 mth	3 2 1	2		1	3 2		1	1		1 m
0 mth		1			1	1				0 m
Skill areas:	Passive Posture	Active Posture	Locomotor	Manipulative	Visual	Hearing & Language	Speech & Language	Interactive Social	Self-care Social	
*Quality										*Qu

*Use an 'X' to indicate concern over quality of performance

Code

APPENDIX C: Client disabilities and characteristics.

The descriptions of each client's disabilities contain variable levels of detail but are a record of the information available to the staff of the different units. Client characteristics were either observed during filming or described by keyworkers. Again, the level of detail is very variable. The number allocated to each client follows the numbering in appendix A.

1. A 32 year old man living in a hospital. He had no known sensory impairments and could walk, but had a kyphoscoliosis; he was epileptic.

He enjoyed investigating cupboards and boxes.

2. Details appear in his listing as client 17.

3. A 39 year old man. He was blind, apparently not perceiving light or dark. He was fully ambulant.

At times he twirled around in circles. He had a few words, mostly slang; he enjoyed physical contact particularly touching women's breasts.

4. Details appear in his listing as client 9.

5. A 32 year old woman. She was blind, believed to see light and dark sometimes but this varied according to how much damage she had recently caused by hitting her eye. She was epileptic and ambulant but walked with extreme difficulty due to high muscle tone in legs. This was thought to be a combination of birth damage and circulatory problems caused by her sitting on them.

During data collection she had periods of screaming which seemed to have no cause but continued for hours: she would also injure herself. Her hunched body posture and refusal to explore or hold things in her hands seemed defensive. Being out for a walk in her wheelchair on a windy day was her greatest pleasure. She also enjoyed sesions in the hydrotherapy pool.

6. Details appear in his listing as client 20.

7. A 26 year old woman. She had athetoid cerebral palsy which gave her almost no independent movement and was complicated by the presence of reflexive movements if she became too aroused. A pleasure response would start with smiles and wriggling but beyond a critical level of movement would become reflexive spinal arching, an uncontrolled facial grin or grimace, and laboured breathing. She was epileptic. Eye-pointing was the response she could make most reliably.

She was selective in making social relationships, clearly signalling her preferences among staff.

8. A 17 year old young man. He had asthma, cerebral palsy, epilepsy, scoliosis and was very short sighted. If over-aroused he would display reflexive movements of his arms and legs but was able to control his face and head movements. Non-ambulant and unable to move his body through space.

He enjoyed the sound of some musical instruments.

9(& 4). A 25 year old man. He had congenital spastic quadriplegia, a dislocated left hip and general atrophy of his bones due to disuse. He had epilepsy.

He had learned how to manipulate his wheelchair and doing so in spacious surroundings was a source of pleasure. He could stand with assistance. He could feed himself but required continual prompting. He liked to have objects in his hands which made a noise and would chew his clothing if this was not available.

10. A 24 year old woman with Downs Syndrome. She had ankle and foot deformities and scoliosis; although ambulant she could not walk far. She was epileptic.

A fairly placid person, she smiled even when she seemed to have hurt herself. Occasionally she would hurt other clients.

11. A 38 year old woman with phenylketonuria. She was ambulant with no known sensory problems.

She was continent and able to feed herself. She made whimpering, crying noises much of the time: staff were not sure whether this had become a habit or whether she was unhappy or in pain. Her main pleasure seemed to be hugging staff or hugging cushions.

12. A 26 year old woman with epilepsy and cerebral palsy. She was partially sighted but staff did not know the nature of her impairment: they thought she seemed to see better in peripheral vision.

She would laugh readily in response to a variety of stimuli, particularly liking the sound and brightness of a foil sheet used to wrap up runners after a marathon.

13. A 22 year old woman with epilepsy. Fully ambulant and skillful in a number of areas.

Her very variable moods were her most characteristic aspect. Sometimes the source of provocation was obvious, such as when the bus broke down and she waited for hours, but she could be angry and unco-operative for a whole day without such events. She would sit like a hunched ball of fury and hit anybody who tried to approach. On a good day she could communicate, speak a few words and be smiling and open.

14. An 18 year old woman with no known medical condition but hypotonia in all limbs, managed by supporting her in a fibre-glass mould in a wheelchair. She had relatively poor control of her limbs and seemed tired if she held her head up for long.

She could hurt other people by pinching. She had learned some Makaton signs. Her most notable characteristic was squealing: whether this was an expression of exuberance, an attempt to irritate or attention-seeking in nature was debated.

15. A 19 year old woman with no known medical condition. Fully ambulant and non known sensory problems, she was independent in toiletting, feeding and washing.

She would wander away from most activities or people when first introduced to them. She would have days when she repeatedly made single loud roars or screams which seemed to be exuberant in nature. She was particularly interested in electronic equipment, enjoyed using the computer and showed interest in the video camera.

16. A profoundly physically disabled 21 year old woman. She had cerebral palsy affecting all four limbs, also epilepsy and spinal scoliosis. She had a dislocated left hip. She was non-ambulant and supported in a mould inserted into a wheelchair, but had head control and a fair range of hand movement.

During filming her health seemed very variable, looking ill and unresponsive on a few occasions (when filming was postponed). Her moods also seemed variable, ranging from smiling and openess to a very expressive glower.

17.(and 2). A 28 year old man with severe cerebral palsy but with full control of arms and head. He had demineralisation of his bones and a kyphoscoliosis which was thought to give him pain. He had epilepsy.

He could scream for periods and showed a range of stereotyped behaviours. He could become agitated at times.

18. A 25 year old woman with gross severe spastic quadriplegia, a deformed hip and epilepsy. She had contracture of both lower limbs with secondary scoliosis: her musculo-skeletal system was degenerating. She had a chronic irritation in one eye caused by continual rubbing.

She enjoyed other people around her joking and laughing loudly and also watching people dance to pop music.

19. A 26 year old woman with severe spastic quadriplegia. She was registered partially sighted but staff felt that she did not even see light and dark.

She showed a variety of stereotyped behaviours including rubbing the back of her head on a chair and masturbating. She was said to enjoy joking and rough and tumble.

20(& 6). A 21 year old man with a visual impairment thought to be of cerebral origin: his eyes will follow bright light but the sight does not seem to be useful. He has a 40-50 Db hearing loss but it was decided not to fit an aid as he seemed to use his hearing as a directional sense and it was feared an aid might confuse him. He has cerebral palsy but can walk; he has epilepsy.

He showed a variety of stereotyped behaviours which caused tissue damage to his face and head. These included hitting his head with a fist, managed by splinting both arms, also banging his head on the floor and bringing a knee up to his cheekbone and jaw. These behaviours varied from day to day and could be accompanied by screaming. On a good day he would enjoy tickling games and rough and tumble.

21. A 34 year old man with cerebral palsy affecting his legs but with full control of his head and arms. His leg problems were exacerbated by poor circulation caused by him sitting on them. He had some internal bleeding thought to be caused by a stomach ulcer.

He enjoyed having a rattle or other noisy object available. He showed stereotyped behaviours which included hitting his head which increased when he was unwell. He enjoyed rough and tumble and tickling games and initiated social interaction with newcomers.

22. A 23 year old man with spastic quadriplegia, left-sided scoliosis and epilepsy. He had voluntary control of his face, head and arms unless his head went too far back when reflexive responses would occur. This was normally prevented by the chair mould he used. His vision was limited by severe nystagmus.

He showed a range of stereotyped behaviours including hitting his forehead and his arms were splinted when he was unattended. He enjoyed looking at photographs and had sounds which he used when happy.

23. A 19 year old woman with one leg shorter causing some motor disability although she was ambulant. She had epilepsy but no known sensory impairments.

She seemed open to social contact and enjoyed being with people.
24. A 37 year old woman of very short stature but ambulant. She is very short sighted and has glasses which she will not wear.

She seemed to enjoy social and physical contact but would also hurt both staff and peers without obvious provocation. She had come up to staff, indicated that she wanted a hug and then bitten their cheek. She also showed a number of stereotyped behaviours which seemed to stimulate her peripheral vision.

25. A 16 year old boy who had recently left school and joined the adult services. No medical condition, no known sensory impairments.

His behaviour included many fast movements and a reluctance to stay in one place. He had a range of stereotyped behaviours. Some of these may have had a communicative function, such as spitting, while others seemed to be fun, such as tapping air-filled cheeks or making noises. He enjoyed trampolining, rough and tumble play, and kissing and hugging his keyworker.

26. A 26 year old woman with a diagnosis of chromosomal abnormality. She had increased tone in her lower limbs; she crawled on her knees but could not walk. She had a kyphoscoliosis, and was very short sighted but had no glasses.

She was socially responsive and intiated contact with newcomers, seeming to prefer this to any other activity.

27. A 21 year old man with epilepsy, cerebral palsy affecting his legs and partial sight.

He could concentrate on one task for hours, moving coloured wooden balls on a hoop from one side to the other for whole afternoons. He showed a range of stereotyped behaviours, usually involving clapping or tapping with his hands (or someone else's) or making mouth noises with teeth and lips. He enjoyed swimming and riding.

28. An 18 year old woman. She had a kyphosis and was blind.

She seemed to be defensive about using her hands, rejecting anything introduced and so doing very little for herself. She only walked when led. She did not explore with her hands. She used people to do things for her, asking for her ears or hair to be stroked, seeming not to discriminate between who might do this and making people feel that this did not have a social quality. She became very distressed in hot weather, stripping and screaming.

29. A 20 year old man with no known impairments and no cause of disability. He had an unsteady gait, seeming to rush forwards as if afraid of toppling over.

He spent much of the time rocking a chair backwards and forwards with his arms up his jumper. This had apparently been encouraged as an alternative to destroying his clothing or hitting himself, although these still occurred when he was distressed. His greatest interest was looking at cars and buses and going out in them. He also looked at toy cars sometimes, enjoying imitating car noises with his mouth.

APPENDIX D: INDIVIDUAL CODING SCHEMES FOR THE STUDIES OF ADULTS WITH PROFOUND INTELLECTUAL DISABILITY.

Some of the following clients were in all of the studies, some in only one. Information on the way their behaviour was coded is compiled into this appendix for completeness and comparison. The numbers allocated to each client refer to the same people who were in appendices A, B and C. There is no information about the clients who took part in the pilot study alone as their behaviour was not analysed in detail.

The coding scheme identified behaviours in four areas. Positive responding was considered to be either a positive social behaviour such as smiling, or a behaviour indicating happiness or contentment such as humming. The latter was recorded regardless of whether there appeared to be a socially communicative dimension. Negative behaviour was also coded both as a socially negative response such as turning away and as a behaviour indicating some negative state, possibly non-social, such as crying or self-injuring. Stereotyped behaviours were the third group of behaviours coded; these included repetitive responses which might be self-stimulating and periods when the client was thought to be responding in an involuntary, reflexive manner. A relatively passive, unresponsive state was coded as 'neutral'. The coding scheme also provided an extra category, 'uncodable', which was generally used if the client moved beyond the camera or whose behaviour could not be coded for some reason.

Clients' individual behaviours were interpreted as one of the four types of responses by the keyworker in discussion with the experimenter. Where opinions differed the keyworker's view was recorded. Details about each client are in the previous appendices. For ease of interpretation their sensory status and physical impairments are summarised here as well.

5. A blind woman with difficulty walking.

Positive:
-a fleeting smile with minimal facial changes
-head up and toward speaker
-head up, weaving it slowly from side to side
-open body position
-vocalising 'hack'.

Negative:
-head far down on chest, body hunched far over
-screaming
-hitting herself
-walking off

Stereotyped:
-none known

6. See 20.

7. A profoundly physically disabled woman with eye-pointing as her most reliable response. Apparently normal hearing and vision.

Positive:
-smile
-look
-reach or touch

Negative:
none known

Stereotyped:
-reflexive responses, back arch.

8. A profoundly physically disabled man with short sight.

Positive:
-smile
-squirm
-look
-reach
-touch

Negative:
-none known

Stereotyped:
-arm and leg extensor reflex.

9. A physically disabled man with full use of arms and face; no known sensory impairments.

Positive:
-looks
-looks and rocks
-smile, including half-smile
-takes keyworker's hand
-alert listening: face and head still, looks slightly to the right of keyworker's face

Negative:
-heavy breathing with frown and outstretched hands
-tapping wheelchair
-moan
-wheel away
-push keyworker

-frown

Stereotyped:
-pulls jumper
-heavy breathe with neutral face
-rocks (not looking)
-fiddle with bangles or box*
-sucking teeth*

*NB if these are combined with a look or smile the positive response should take precedence.

10. An ambulant woman with no known sensory impairments.

Positive:
-looks*
-reaches*
-holds hand
-smile*

Negative:
-hand(s) over eyes
-sighing
-hide face with jumper
-hit face*

Stereotyped:
-rock*
-pull jumper*
-swing leg*
-flick finger at corner of eye*
-fiddle with finger*
-grind teeth*

*NB reach with any stereotyped behaviour, code positive:
smile and/or look with self-hit, code negative.

11. An ambulant woman with no known sensory impairments.

Positive:
-reach to hug
-look
-smile
-hug self
-pull keyworker towards herself

Negative:
-head averted
-spits

Stereotyped:
-hand-wringing
-swallowing
-rock side to side
-whimpering noises
-sucking teeth
-banging teeth together
-body-writhing
-flick fingers before eyes

12. An ambulant woman who was partially sighted.

Positive:
-laugh
-smile
-head up toward keyworker
-looks

Negative:
-screws up face
-hide face with jumper
-turn away
-head down

Stereotyped:
none known

13. An ambulant woman with no known sensory impairments.

Positive:
-vocalise
-look
-smile
-clap
-touch keyworker

Negative:
-walk off
-push keyworker
-hit keyworker
-head held down on chest

Stereotyped:
banging hands on knees

14. A hypotonic woman with limited control of face and hands: no known sensory impairments.

Positive:
-look
-smile

-click with tongue
-vocalise
-reach to keyworker
-touch keyworker
-makaton sign for yes (right fist 'nodded' at top of arm held up)

Negative:
-turn head away

Stereotyped:
squeal with arched back

15. An ambulant woman with no known sencory imapirments.

Positive:
-look
-sign yes (fist nodded)
-sign please (stroke chin)
-reach to keyworker
-vocalises
-flips lowere lip
-responds to questions with any sign

Negative:
-walks off
-stands up

Stereotyped:
-none

16. A physically disabled woman with reasonable control of head, face and arm movements: non known sensory impairments.

Positive:

-look
-smile
-eyebrows up in response to a comment or question
-turn head toward keyworker

Negative:
-turn head away
-frown with furrowed brow

Stereotyped:
-fiddle with fingers*

*If this combined with look or smile code positive.

17. A physically disabled man with control of arms and face; no known sensory impairments.

Positive:
-look*
-smile
-rock*
-reach to hold keyworker's hand

Negative:
-agitated body movements
-knees drawn up with body sharply 'shut'

Stereotyped:
-hands in mouth*
-hands waving
-rock with knees up
-nose flick with finger
-crooning

*NB if look or rock combine with hand in mouth code positive: if look or rock are combined with any other stereotyped behaviour code stereotyped.

18. A physically disabled woman with control of face and head, some control of arms. No known sensory impairment.

Positive:
-look*
-smile
-laugh

Negative:
-cry
-squirm
-turn head away

Stereotyped:
-rub eye*
-grind teeth*
-hand in mouth*

*Teeth grind or eye-rub combined with look, score stereotyped. Hand in mouth plus look, code positive.

NB slow eye-blinks of over half a second were scored as a neutral second even if they were in the middle of a sequence of another behaviour.

19. A physically disabled woman with control of face, head and arms. She was registered partially sighted but thought by staff and experimenter to be completely blind.

Positive:
-highly pitched squeal or noise

-smile
-face turned to keyworker
-squirm with smile

Negative:
-low pitched moan or grunt
-push keyworker with hand
-bang hands together

Stereotyped:
-move head so that the back of it is rubbing against the chair*
-hand inside trousers with rubbing.**

*If this is combined with a smile or appear that her head is toward the keyworker it should still be coded as stereotyped.
**Sometimes hand down trousers seems to be a 'settling' behaviour without rubbing; if this is so and there is subsequent smiling it should be coded as positive.

20 (& 6). An ambulant man with partial hearing and partial vision.

Positive:
-laugh
-smile
-right arm quiver
-right leg banged on floor or kicking chair
-'weaves' head while smiling
-head toward keyworker, still and alert

Negative:
-screws up face
-moans
-knee up to hit face
-head bang on floor

-hit face with hand

Stereotyped:
-rub face on sleeve
-head down between arms, weaving it without a smile

NB use 'uncodable' if his face is obscured while he is moving about rapidly.

21. A man with difficulty walking but full control of arms and head and no known sensory impairments.

Positive:
-laugh
-smile
-look
-reach to keyworker
-touch keyworker

Negative:
-vocalised loud "aargh" with angry face
-moaning
-hit head with fist

Stereotyped:
none

22. A profoundly physically disabled man with control of arms, head and face. Limited vision due to severe nystagmus.

Positive:
-look at keyworker
-turn head toward keyworker
-vocalise

-rock
-kiss air
-smile (NB this sometimes difficult to judge as he has his mouth open in the neutral position. Score this if some feature of "warmth" also seems to be present)

Negative:
-push keyworker away
-scowling expression

Stereotyped:
-scratch teeth
-scratch hair/head
-grind teeth
-hit self on forehead

If any stereotyped behaviour occurs in combination with another behaviour it should always be coded as stereotyped.

23. An ambulant woman with no known sensory impairments.

Positive:
-look
-smile
-reach and touch
-vocalise

Negative:
-crumpled face

Stereotyped:
-face brought steadily forwards until it is very close to the keyworker's (within about 18 inches if that can be judged from the camera angles)

24. An ambulant woman with very short sight.

Positive:
-look*
-touch

Negative:
walk away
-pinch
-scratch
-turn face away

Stereotyped:
-screech
-hand over ear and hum
-wave hand at periphery of eye
-stare at hand

*NB if look is combined with negative behaviour, code negative; if look is combined with stereotyped, code stereotyped.

25. An ambulant young man with no known sensory impairments.

Positive:
-look
-smile
-hold keyworker's hand
-lean body toward keyworker

Negative:
-head down
-face covered with hands
-turn away
-walk off

Stereotyped:
-filling cheeks with air and patting them
-making funny noises
-spitting
-overbreathing

If any positive behaviour occurs with any stereotyped one, code stereotyped.

26. A physically disabled woman who could crawl and had full use of arms, head and face. She was very short sighted.

Positive:
-look toward keyworker
-reach
-clap hands
-flap hands
-smile (difficult to judge, a minimal facial change. Look for additional signs of warmth in her expression such as creased cheeks)

Negative:
-squirm off chair
-complaining noise
-scowl

Stereotyped:
none

27. A partially sighted man who was non-ambulant but had the use of his arms , head and face.

Positive:
-look
-smile

-clap his hand on keyworker's

Negative:
none

Stereotyped:
crooning noises
-mouth-play (eg bbrrrr)
-fiddling with shoe-laces

If look is combined with stereotypred bvehaviours code positive

28. A blind woman who can walk but only does so if led.

Positive:
-head up and toward keyworker
-smile
-laugh

Negative:
-squirm
-push keyworker
-kick keyworker
-pull own arm away from keyworker

Stereotyped:
none

29. A man with no physical or sensory impairments.

Positive:
-look
-smile

Negative:
-back away
-turn away
-walk off
-hit self
-hunched over, fists clenched to eyes, rocking and squealing

Stereotyped:
-humming and other noises
-rocks
-knocks chin
-sitting upright with fists clenched to eyes

If any positive behaviour occurs with a stereotyped one, code stereotyped.

APPENDIX E QUALITATIVE DESCRIPTION OF THE INTERACTION BETWEEN EACH PAIR.

Numbers refer to those allocated to keyworker-client pairs in appendix A. Details of the client's abilities as assessed by the SGS are in appendix B. Details of the client's disabilities are in appendix C. A description of the way that each client's behaviours were interpreted is in appendix D.

The following descriptions give two types of information. Episodes identified by a dash (-) are those which both raters independently selected as a social exchange between the two parties, the interpretation of which was also made independently and subsequently agreed. Notes at the end of the session concern global impressions of the interactions. These were agreed by the two raters in discussion after they had carried out their independent assessments.

K refers to the keyworker and C refers to the client.

Pair 9.
(Session 1)
-c looks at bed, k changes topic to comment on the new bedcovers.
-c coughs, k retreats and then requests an alternative behaviour by word and demonstration.
-k talking animatedly, c gives long period of calm eye-contact.

This session was characterised by a number of small exchanges of looks which were usually accepted by k returning the look but showing no other change. Once k responded more supportively by smiling and welcoming the eye contact.

(Session 2)
-c takes k's hand, k accepting without comment.
-c releases k's hand which k accepts without comment; c then smiles and rocks which is welcomed by k smiling and making a positive

comment.

-c fiddles with clothing which is prevented by k., c overbreathes in response.

-following further conversation c again starts to rock and overbreathe, understood by k to be an objection, responded to by k pausing and leaning back away from c.

-a few seconds later k leans toward c and starts talking again; c rejects this and k again leans back.

Pair 10

(Session 1)

-k asks a question, c breaks eye contact and covers face with hands.

(Session 2)

-c looks, k accepts.

Only a small number of discrete events were identified by each rater and agreements on which ones were socially interactive were low. Both c and k at times gave the impression of co-existing in parallel rather than mutually influencing each other. Both had a relatively limited set of social behaviours. If they were being described in drama terms their body language would be characterised as 'mumbling'.

Tone of voice or affective style seemed to be an area of sensitive communication between these two. K made a "joking" comment about c's misbehaviour: C seemed to hear the criticism and responded by concealing her face.

Pair 11.

(Sessions 1 & 2)

Most of the behaviours which were agreed on for these two sessions concerned k reaching to touch c who accepted the approach without encouragement.

These sessions had a fairly restricted flavour, both parties showing little variation in behaviours such as affect, level of animation, positioning or facial expression. Most of the interaction seemed to come from c's use of touch and changes of proximity.

Pair 12.

(Session 1)

-c makes eye contact, smiling and looking shy or embarrassed or coy; k had asked a question and responded acceptingly.

-c initiates eye contact while k is talking. k accepts without change in style. The contact again has this coy flavour.

-k had a warmer tone of voice and smile, c smiled and laughed and k accepted this.

(Session 2)

-c looked briefly then looked down and moved the chair back a bit. k leaned forward more in response.

-k. calls c.s name and tries to gain attention; c gives eye contact which is met supportively by k.

These interactions occurred at a fairly close proximity. When eye contact occurred it was fleeting. It is possible that the particular nature of c.'s visual impairment made focussing on someone near very difficult and that social interaction would have been facilitated by the parties being positioned further apart. It appeared at times that c was trying to indicate that a larger distance would have been more comfortable but that k's goal was to maintain a fairly close proximity.

Pair 13.

(Session 1)

-c reaches to k and then pats knee instead. k interprets this as a reference to a visiting baby in the unit, making appropriate comment in supportive manner.

-c looks, smiles, claps; k responds with face and voice to welcome this new behaviour.

-k leans forward with head held lower as c had head down. c accepts this.

-while k is talking c takes k's hand, a gesture accepted by k.

-A few seconds after this c says k's name, k repeats supportively and with pleasure and they take turns saying this for a few seconds.

-c walks off, apparently wanting to see the visiting baby. k remains and talks about the session ending in a few moments. c returns to stand by k with 'marching' feet.

-c walks to door but does not leave.

(Session 2)

-c standing during session, some walking away and then returning to stand by seated k. k starts to talk of cars making appropriate noises, c imitates, they take turns exchanging car noises.

-c sits down, k welcomes this verbally.

-c hits own hand and then proffers the hit hand to k. k continues talking. This is repeated and again not commented on by k. On the third occasion k comments on the profferred hand.

-c takes k's hand in an apparently confident gesture, k accepting this.

These interactions have much activity but also present difficulty as c also walks off and stands rather than sits.

Pair 14.

(Session 1)

-k says c's name; c responds with a tongue-click and looks, k welcomes this.

-k asks question, c responds with tongue-click, k accepts.

-c makes eye contact while laughing and squealing. k discourages this but c continues.

-k asked a question which c answered with a signed 'yes' which is supported by k.

-k asks a question which c responds to with a tongue-click, k accepts this.

(Session 2)

-k asks c to look and c does, also smiling; this is supported by k.

-k asks a question and c responds with a signed 'yes'.

-c drops head while k talking. k asks for c's attention, c looks and smiles and k welcomes this.

It was inevitable that question-and-answer sequences would be more easily agreed as major exchanges than others and it would be unjust to suggest that the sessions between these people were limited to this sort of exchange. However, the use of questions was frequent and the varied systems used by c in attempting to co-operate impressive. Both raters had the impression that c did not understand the questions and was trying to please in making responses. That c understood the social requirement to make some response to a question seemed an important ability.

Pair 15.

(Session 1)

-on 6 occasions during this session c shouted while looking at k. Raters were unable to agree on the nature of k's reaction, despite having seen the videotape on many occasions. It could be seen as surprised interest or as joking disapproval.

-c looks and leans forward, k accepts.

-k asked a question, c signed 'yes'.

(Session 2)
-k asked c to turn head, c responded by touching hands to head and looking at k. k accepted this response.
-c looks away when k was pausing, k asks for attention and c looks.
-c looking away, k says c's name sharply, c looks.
-k initiates conversation about swimming which includes k making swimming movements with the arms and inviting c to copy. c seemed to be hesitant about what was required, touching k's hands as they approached and retreating as k withdrew them round to complete the breast-stroke movement. It seemed possible that this was not an example of mutual exchange but of both parties having a different agenda. As was noted with a previous pair, the notable feature may be an attempted interaction from k and an attempt to co-operate from c.

The most important global comment from this interaction was the response from k to c's shouts. It must be vital for staff to give clear social cues and not to say things in a tone of voice or with an expression which could have more than one interpretation.

Pair 16.

There were no major exchanges which both raters agreed on in the first session and only 2 in the second. C. was very physically disabled and unable to move: it may be difficult for somebody with such disabilities to make clear gestures which will be universally interpreted as interactive by observers.

It was felt that the overall impression of the interactions was nevertheless important and something which both raters did feel confident about. C avoided eye contact almost all of the time while k maintained a close body proximity which seemed over-intimate. When c moved so that c's head was averted down or to the side k would also move to try to gain eye contact by twisting upwards from below c. On two occasions when k could not think of anything to say and requested a prompt from the experimenter c looked up while k was looking to the experimenter only to look away when k returned to talk to c.

Pair 17.

Another profoundly physically disabled client for whom the raters could not agree on which events were key interactions. However, these sessions were more low-key in style, with social exchange occurring in a manner described as 'lacklustre' by one rater, 'minimal' by the other.

Pair 18.
(Session 1)
-c. moaning, k rejecting this by talking more loudly over c's noises.

(Session 2)
-This session contained a number of exchanges of looks from c and one smile.

A profoundly physically disabled client who provided the raters with few responses which could be agreed. However, the global impression of the second session was that it contained very much more pleasure and sustained contact between the parties. This was shown in sustained looking and smiling which could not be described as interactive exchanges. k's seating position was thought to be one contribution to this change, sitting directly in front of c in the second session rather than to one side.

Pair 19.
(Session 1)
-head away from k while making moaning sounds which k accepts.
-c orients head toward k which k accepts.

(Session 2)
-c attempts to put hand down trousers, k prevents.
-c. tips head right back, k comments and asks c to sit up, c does and k accepts.
-c. turns away from k and successfully puts hand down trousers with a smile.

A profoundly blind person whose stereotyped behaviours were difficult to distinguish from positive responses. The limited number of agreed behaviours were due to that confusion rather than the absence of events. These sessions included signs of pleasure between the two people at times.

Pair 20.
(Session 1)
-c leans forward to put head on own knee, k sitting beside c accepts this.
-c sits up and k accepts this, continuing to talk.
-c takes k's hand and uses this to lower self to floor, k supporting this while preventing c from actually lying on the floor. They continue to hold hands.
-c hits head.

(Session 2)
This tape had no agreed social exchanges. However, during the session c sat leaning against k smiling. k had said in discussion that a positive session with c would probably involve no self-hitting or shouting. Although c's head was down while smiling so k could not see it, it is likely that k felt the session was positive because of the absence of negative behaviour. There was little evidence of interaction or exchange

as c and k remained in essentially the same positions during the session.

These sessions raise the issue of recognising interaction when nothing visible is occurring. It is known that in some situations 'stilling' indicates attentive listening, while in others it indicates caution or wariness. Perhaps some consideration of that would be useful, particularly when considering a client such as this who has impaired vision and hearing.

Pair 21.

(Session 1)

-c puts arm around k, hugging k's head to own body. k supports this with laughter and by not avoiding very assertively.

-k extracts self from embrace laughing, head again pulled down by c grabbing hair playfully.

-A number of exchanges of this occur over the first two minutes, with laughter on both sides and mock-objection from k. Following further talk the session ended with another episode of this teasing initiated by c.

(Session 2)

-c and k move heads toward one another, both looking and smiling and k using animated voice with considerable variation in pitch.

-c smiles and bows head toward k's so that they touch. -c seemed to be responding to k's warm tone of voice.

-c hugs k's head with a smile, supported by k.

These sessions were very active physically. The interactions showed turn-taking and initiation from c. Raters struggled to describe k's voice-quality, which seemed to please c. It contained variations in pitch, tone and level of animation. Speech was carried out from a proximity which could only be characterised as intimate. Sensual might be an accurate description. The interaction had a physical and intimate nature.

Pair 22.

(Session 1)

-k asked a question, c. rocks and vocalises, k supports by imitating the sound.

(Session 2)

-c vocalises k supports.

-k leans forward touching c's clothing; c accepts this.

-k leans back in the chair and then forward again. c accepted these changes without obvious response.

-k again leaned forward, c accepting.

-c looks, k accepting without obviously responding.

-c again turns to face k, k accepts.

These interactions were carried out at a social distance generally described as impersonal or that used by strangers. k leaning forward from such a position would probably have a different effect than if k was starting from a closer position.

There was difficulty in selecting discrete events which could be agreed in the first session, although the second gave more room for agreement.

Pair 23.

(Session 1)

-c leans forward so that c's body is doubled over and c's face is nearer k's; c's head comes up to touch k's and k supports by laughing.

-c leans back while looking and laughing, k accepts without obvious response.

-c leans closer again which k accepts.

(Session 2)

-c leans over double and closer to k; k accepts and then asks c to sit up.

-c does sit up in response to the last request, k supports.

-c looks around the room, k accepts.
-c faces k and smiles, claps and laughs. k accepts.
-c leans forward k accepts.
-c sits back while smiling and looking, k accepts.
-c leans forward again,k accepts.
-c leans back, k accepts.
-k asks c to raise c's head, c does so and k supports.

The main question for the raters in interpreting these exchanges was whether the frequent changes in body posture were interactional in nature, concerned with relating to k, or whether they were movements and changes which interested c for their own sake. K believed they were stereotyped movements which were not social. However, the more the raters viewed the tapes the more they felt that c was trying to initiate a game with k similar to children's peek-a-boo.

Pair 24.
(Session 1)
-c touches k's hand and turns to face k; k accepts.
-c touches k's hand and leans forward, k accepts.
-c looks at k who accepts this.
-c looks at k who accepts.
-c stands up to sit on k's knee, k rejects this and c remains standing beside k.
-c takes k's hand k accepts.

(Session 2)
-c leans forward to take k's hand, k rejects this.
-c leans forward to take k's hand who again rejects this.
-c leans forward to touch k who rejects this. c then shows stereotyped behaviour.
-c leans forward to touch k who avoids this contact. c then shows

stereotyped behaviour.
-c looks at k who accepts.
-c turns away from k who also accepts.

Pair 25.
(Session 1)

This session contained considerable activity but no agreement between raters about which exchanges represented key interactions. c's movements were quick and flowed into each other, possibly making it difficult for k to select discrete behaviours to respond to and certainly making it difficult for raters.

(Session 2)
-c hugs k who gently discourages over 15 seconds until c is guided into a seat which c accepts.
-k touches c who leans back seeming to avoid eye contact.
-k brings face nearer while repeating a word, c shifts away in chair and k brings own face closer.
-c looks and pushes k away. k accepts briefly but then leans forward again.
-k asked c a question and used c's name; c pushed chair back and k responded by pulling the chair closer again.

These sessions were active and both people seemed to be having fun at times. It was difficult to judge whether k was overwhelming c by leaning fairly close and ignoring c's attempts to create greater interpersonal distance. An alternative view could be that c tended to avoid social contact by either darting off or hugging, which placed c in a controlling position. This may be most appropriately handled by ignoring minor cues from the client that they would like more space and assisting c to experience positive interaction. k reported this was her strategy and c appeared to enjoy the interaction at times.

Pair 26.

(Session 1)

-c reaches to k's hand which k accepts.

-c looks, k accepts.

-while c looking k touches c's clothes, c either avoids or looks down at k's hand which c then takes.

-c looks away which k accepts.

(Session 2)

-c reaches for k's hand which k supports by leaning a little forward.

-c pushes k's hand away with a squeal, k accepts.

-c takes k's hand and moves it to c's knee while looking. k understands this to be a request to rub c's knee, acknowledging that the request is understood by explaining this will be done afterwards. c accepts, not persisting in this request.

-c reaches to take k's hand, k accepts.

These sessions were carried out at an "intimate" social distance which appeared comfortable for both parties.

Pair 27.

(Session 1)

-c reaches for k's hand, k accepts.

-c drops head to look at k's hand and play with it, k accepts.

-c puts head back, smiles claps and then over-breathes. k accepts.

-c head down to play with k's hand, k initially accepts and then avoids. c supports this by looking at k.

-k asks a question, c responds by looking at k which is supported.

(Session 2)

-c starts by looking at k which k welcomes.

-c drops head to look at k's hand which c is holding, k accepts.

-c touches k's face, k initially avoided then accepted.

-c clapping, squealing, bouncing, k accepts.
-c turns away from k, k accepts.

These sessions seemed to be dominated by c's gradual reduction in stereotyped behaviour and growth of fascination with k. c seemed particularly interested in watching k's face and mouth during talk sessions.

Pair 29.
(Session 1)
-c makes brief eye contact with a slight smile which k accepts.
-c makes eye contact for a few seconds which k supports.
-c makes brief eye contact which k accepts.

(Session 2)
-c starts by head down on arms, rocking and backing chair away which k acknowledges supportively.
-c puts hands to eyes, backs chair further away and moans, k initially discourages this and when c stops k supports this.
-c again buries head in arms and moans, k discourages and supports its ending.

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