People with learning disabilities’ accounts of friendship

Thesis

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Version: Version of Record
People With Learning Disabilities' Accounts Of Friendship

Volume One

A thesis submitted in partial fulfilment of the requirements of the Open University for the degree of Doctor of Clinical Psychology

July 2000

19 989 Words
Acknowledgements:

Many thanks to the manager and staff of the Community Support Team who all encouraged and supported me in carrying out this study. They also provided invaluable assistance in identifying participants. I would also like to thank all of the people whom I interviewed for giving up their time to take part, and speaking so openly with me about their experiences.

Finally I am very grateful to Dr. Jan Burns for her continuously calming support and supervision, which was of great assistance to me in completing this project.
Abstract

This study aimed to investigate how people with learning disabilities construct accounts of friendship, and manage aspects of a 'spoiled identity' within this. Furthermore it aimed to investigate how the typical processes of friendship formation are affected by the management of such an identity. It was suggested disclosure of personal information can be anxiety provoking for them and the choice of analysis needed to focus on deconstructing their accounts for linguistic devices used to manage difficult issues and then consideration could be given to the functions of these devices.

Eight people with mild learning disabilities, four men and four women, were recruited to the study. Having obtained their informed consent each was interviewed using a semi-structured interview schedule focusing upon aspects of friendship formation identified within mainstream literature. In view of the aims of the study it was decided the most appropriate form of analysis would be discourse analysis.

At a surface level the experience of the participants mirrored that found in previous research. In addition a number of rhetorical devices were identified. Further consideration of these revealed they were used at times in the interview when either participant or interviewer was attempting to manage an issue related to difference or stigma. In view of this it is argued that managing a stigmatised identity directly impacts upon typical processes of friendship formation.

The findings are discussed; consideration is given to service and research implications. It is suggested that awareness of the nature and function of rhetorical devices could facilitate professionals in helping people with learning disabilities to discuss their difficulties and associated emotions in a more meaningful way. Enabling people with learning disabilities to develop higher self-esteem is discussed in relation to them attributing more value to friendships with others with similar disabilities, and the development of the self-advocacy movement.

300 words
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CHAPTER ONE - INTRODUCTION

The presence of a supportive social network has been shown to be a protective factor against mental illness (Brown and Harris, 1978), yet research (Richardson and Ritchie, 1989) and clinical experience have highlighted the impoverished nature of the social relationships of people with learning disabilities. Under the influential ideologies of normalisation, (Wolfensberger, 1972) and later, Social Role Valorisation (SRV) (Wolfensberger, 1983, 1984) the move away from institutional to community care was underpinned by an emphasis on the need for people with learning disabilities to be facilitated in obtaining valued social roles. It was hoped that by having a presence within local communities people with learning disabilities would be able to integrate with people who are not disabled, thereby obtaining more value in the wider society. Thus a key aspect of this process of integration was the building of relationships between people with and without learning disabilities. However, simply placing people into communities has been insufficient to enable them to build such friendships (Jahoda, Cattermole and Markova, 1990). Furthermore implicit within SRV was the notion that grouping stigmatised people together served to maintain their negative value, thus any friendships between people with learning disability were indirectly devalued by this ideology (Szivos, 1992).

Various research studies have highlighted the pragmatic and social constraints which hinder people with learning disabilities from developing friendships (Chappell, 1994). Yet little attention has been given to the actual processes involved in making friends. To understand something of how these processes typically occur there is a need to consider mainstream theories of relationship formation and how these are affected by membership to a socially devalued group. The issue of how awareness of a stigmatised
identity affects the process of building and experiencing friendships for people with learning disabilities was the focus of this study. It was thought probable that participants with a learning disability would find it challenging to talk openly within a research context about the impact of their stigmatised identity on making friends. Goffman's (1963) work on management of a spoiled identity highlighted how people who are stigmatised employ strategies of 'passing' or 'covering' within interactions with 'normals' to manage identity disclosure. Such strategies arguably manifest within spoken interactions. As a result, it was felt necessary to use a form of analysis which would assist in identifying any speech strategies people with learning disabilities use to manage difficult or anxiety provoking aspects of the interaction, and what the nature of these difficult aspects were. It was hoped that by gaining a deeper understanding of these issues and how they are masked by people with learning disabilities in their language use that professionals working with them can gain further insight into the complexities of friendship formation, and develop therapeutic and pragmatic strategies to facilitate friendship development.

The remainder of the Introduction will begin with a brief discussion of the links between friendship and mental health. Then the policies governing the management of people with learning disabilities will be briefly reviewed in order to reflect something of the way in which they have been segregated and labelled in stigmatising ways. Following this, in order to provide a theoretical framework within which to understand the processes behind the development of a stigmatised identity, Goffman's (1963) work on stigma will be reviewed. This will include consideration of the impact of stigma on a more micro level: in one to one interactions between people with and without stigma. Research focusing on whether people with learning disabilities are
aware of being stigmatised will then be reviewed. Having established the impact of stigma on the individual with learning disabilities, the focus will then turn to previous research findings about their friendships. It will be suggested that whilst these have identified pragmatic constraints, and more social issues related to group identity, they have failed to examine the impact of a stigmatised identity on the process of making friendship. In order to understand something of these processes mainstream theoretical literature will be reviewed, highlighting skills required and possible difficulties for people with learning disabilities. Following this Goffman’s theories on how stigmatised people manage a 'spoiled identity' (1963) will be returned to which will lead into consideration of the role of language use in creating and managing one’s identity. Finally the aims and broad research questions will be outlined.

1.0 The relationship between friendship and mental health

Having supportive personal relationships has been shown to be positively linked to quality of life (Clegg and Standen, 1991; Newton, Olsen, Horner and Ard, 1996, Donegan and Potts, 1988) and generally as a protective factor against psychological illness (Brown and Harris, 1978; Duck, 1986). The absence of such relationships can result in depression, loneliness, low self-esteem and a sense of social failure (Chappell, 1994, Richardson and Ritchie, 1989). The recent National Service Framework for Mental Health (Department of Health, 1999) also highlights how tackling social exclusion is imperative in reducing the incidence of mental health problems. This is based on findings that suggest this is a major factor in the occurrence and maintenance of depression and other psychological difficulties.
Research has shown people with learning disabilities have limited social relationships, and given the above this places them at risk of mental health problems. To begin to understand the paucity of their relationships it is important to consider the historical and social context of learning disability services.

1.1 A History of Segregation: Hopes for Integration

During the Victorian era people with learning disabilities came to be identified with deviance, crime and the downfall of society (Brown, 1994). In line with social practices of the day they were segregated in institutions away from the remainder of society. Little consideration was given to their rights or wants, including their right to have relationships. With the arrival of deinstitutionalisation and the growth of community care, many moved into smaller group homes within local communities with integration into society as the aim. However, as this policy shift was greatly influenced by the principle of normalisation or SRV, the focus of attention on their relationships was on their ability to develop relationships with people who did not have a learning disability. Szivos (1992) suggested that whilst many positive things resulted from the philosophy of normalisation, it assumed that assimilation into mainstream culture was a good thing and that to be accepted, disadvantaged people such as those with a learning disability, needed to aspire to idealised societal norms. Such assumptions reflect a failure to accept difference or attribute it its' own value. As a result of which normalisation as a philosophy has done little to promote self-acceptance or self-worth for people with learning disabilities (Szivos, 1992; Brown and Smith, 1989). Attributing social value to friendships with people who are not learning disabled arguably detracted from the value of friendship with others with a similar disability. As Szivos (1992) suggested
this led people with learning disabilities to reject and devalue their friendships with other such people.

From Szivos' and others (Jahoda, Markova, and Cattermole, 1988; Turner, and Gallimore, 1979) work, it can be seen that being labelled as different - a negative difference at that - has had a profound affect on the self-image of many people with learning disabilities and their relationships. The fact that they too devalue friendships with others similar to themselves reflects their awareness of how they are perceived within society. In an attempt to understand something of the processes involved in stigmatising, Goffman's (1963) work is considered below.

1.2 Stigma

Goffman (1963) viewed acquiring stigma as a social process. He described how societies establish means of categorising people. When an individual has attributes which mark them as different from the norm, and these attributes are undesirable they are reduced in the minds of 'normal' individuals to devalued or unacceptable people. Once someone has been categorised as stigmatised they are then vulnerable to various forms of discrimination.

Goffman (1963) described the effects of stigma on self concepts. He suggested that the stigmatised person is aware of social norms, how they do not match up to these and how others might perceive this as their failing. As a result, for Goffman the term stigma was also associated with shame.
For Goffman (1963) then the experience of being stigmatised is constructed through the social world, and it is within this social environment that the individual must manage their stigmatised identity. It is within social interactions with people who are not stigmatised ('normals') that such management takes on a crucial importance. Goffman described stigma as impacting upon the individual who is stigmatised and the 'normal' person also. Both are involved in the management of the differences between them. Such management may involve avoiding social interactions, but when they do enter into interactions Goffman suggested both must confront and deal with the causes and effects of stigma. For the stigmatised individual there may well be extreme anxiety at how they will be received and judged by the 'normal' person. Furthermore, when the 'normal' person appears to be demonstrating acceptance the stigmatised individual may remain uncertain whether this is genuine or not. Such a situation inevitably leads to discomfort on both sides and a very complex process of social interaction. As Goffman suggested it is probable that such interactions "will not go too smoothly" (p. 30).

Previous researchers have drawn upon Goffman's theoretical framework in relation to the experiences of people with learning disability. Some of the important findings from this work are reviewed below.

1.3 Stigma and People with Learning Disabilities

In Edgerton's (1993) comprehensive longitudinal anthropological study of people with learning difficulties he found that the stigma associated with having lived in an institution and having a learning disability affected every aspect of their lives. He found that all of them invested a great deal of effort employing the process of 'passing' to achieve non-learning disabled personas. Turner and Gallimore (1979, cited in Zetlin
and Turner, 1984) found that their mildly learning disabled participants also “employed adaptive techniques to defend the integrity of their self-concepts” (p.94). Edgerton and Bercovici (1976) found that over time the need for their participants to use adaptive techniques reduced or became insignificant. However other studies, such as Turner and Gallimore (1979) found that stigma was an on-going concern and techniques for coping with it continued to be a life-long aspect of their experiences in the social world. A later study by Jahoda, Markova and Cattermole (1988) found all participants with a learning disability were aware that others’ did perceive them as having a stigmatised identity and recognised their need to cope with this in their daily lives.

Thus, research has indicated that many people with learning disabilities are aware they are perceived as stigmatised, and many adopt strategies for managing this. Before considering this information in relation specifically to its impact upon their friendships, it is important to reflect upon what previous research on friendship has revealed about the experiences of this population.

1.4 The friendships of people with learning disabilities

With the development of community care and the influence of SRV research interest grew regarding the friendships of people with learning disabilities. Yet as Chappell (1994) suggested, in line with the principles of SRV much of this focused upon the abilities of people with learning disabilities to integrate and establish relationships with people who do not have learning disabilities. Typically studies found that this was not occurring.
1.4:1 **Who are their friends?**

Richardson and Ritchie (1989) conducted a major review of the friendships of people with learning disabilities living in a variety of settings in the United Kingdom. They found that the majority of friendships were with other people with learning disabilities who they mixed with at special clubs or day centres. Atkinson and Ward (1987) found that twice as many had friends who had a learning disability as opposed to friends who did not.

1.4:2 **The nature of the relationships**

Richardson and Ritchie (1989) investigated to what degree friendships provided intimacy, company and practical help. They found mixed results: whilst generally the need for practical support was met, a sense of intimacy was often missing. Whilst most had some source of company this was often not of the chosen kind. Generally company was obtained during the day from other people with learning disabilities. Relationships were often an extension of having lived with each other previously or sharing the same day time activity. Most of their participants did have a special friend who was often another person with a learning disability. They recognised the emotional support provided by having such a special friendship although it was not always the friend who they turned to for advice and support; family or staff were consulted for these issues. They also found that having a number of people who they described as friends was no guarantee of quality. Some of their participants listed numerous friends but no real sources of intimacy or warmth.
1.4:3 A lack of friendships with people without a learning disability
Atkinson and Ward (1987), and similarly Jahoda, Cattermole and Markova (1990), found that it was not that people with learning disabilities did not have friends but that they lacked friendship with people without a learning disability. This caused them to feel disappointed with their inability to form such friendships. They also found that integration into mainstream activities or schools alone was insufficient to foster the development of relationships between people with and without learning disabilities.

1.4:4 Relationships with staff
Newton, Olsen and Horner (1995) found that the majority of community members in stable relationships with people with learning disabilities were, or had been, staff employed in services providing care for them. They argued that these relationships should not be underestimated in terms of importance to people with learning disabilities.

1.4:5 Implications on Mental Health for People with Learning Disabilities
The existence of a network of friends may make the difference between integration and isolation for people with learning disabilities living within the community (Barber and Hupp, 1993). As satisfactory networks were not developing the findings implied people were remaining isolated (Donegan and Potts, 1988; Richardson and Ritchie, 1989), and thus likely to be experiencing the negative effect which social exclusion and isolation have on mental health. This was likely to be manifesting in psychological problems, challenging behaviours and heightened impairments as means of increasing interactions with support workers.
As it became clear that people with learning disabilities were remaining isolated a number of researchers attempted to identify what the constraints in friendship development were for people with learning disabilities.

1.5 Constraints in developing friendships

1.5:1 Social Skills

Le Touze and Pahl (1992) suggested that social skills training should be given further attention. Newton, Olsen and Horner, (1995) argued that people with learning disabilities should be encouraged to develop social skills to facilitate relationship stability. However, a later study by Newton, Olsen, Horner and Ard, (1996) found that in general social skills were a poor predictor of the stability of relationships. In conclusion they suggested that social skills training alone was insufficient to secure stable social relationships.

1.5:2 Lack of Autonomy

Chappell (1994) discussed how lack of: income, access to transport, financial provision and privacy inhibited the ability of people with learning disabilities to socialise and develop friendships. However, Donegan and Potts (1988) found that people who lived alone in the community were also often lonely. Whilst they too may have been limited by financial constraints, factors such as privacy and autonomy were arguably not inhibiting them, and yet the problem of lack of friends remained.

1.5:3 Lack of Acceptance

Jahoda, Cattermole and Markova’s (1990) qualitative study found that people with learning disabilities living in the community had not felt accepted by people without
learning disabilities, and felt aware of, and disappointed by their failure to develop such friendships. This was described as a constant reminder of their marginal social status and of their experiences of being teased and rejected by people without disabilities.

1.5:4 Summary of research findings

Research indicated that the majority of those who did have friendships were friends with other people with learning disabilities. Furthermore, most of these friendships developed out of attending special services and not as a result of integration into mainstream leisure pursuits. Thus the aims of SRV with regard to integration did not appear to be occurring. The relationships they had often did not provide a sense of intimacy. Situational factors, such as living environment, lack of funds, and lack of social skills had appeared to be insufficient alone to explain why friendships were not developing between people with and without learning disabilities. People with learning disabilities were found to be lonely, isolated and feeling unaccepted. Furthermore the lack of friendships with people who did not have a learning disability often resulted in feelings of inadequacy and failure.

However, research thus far has failed to offer a comprehensive understanding of what factors may be hindering people with learning disabilities in making friends. Whilst clearly all of the factors studied play a significant role in complicating the process of making friends, what has not been attended to are the typical processes of developing friendship and the impact that being learning disabled has on this. In order to understand something of these processes it is necessary to consider the mainstream theoretical literature on friendship formation.
1.6 Mainstream theories of friendship formation

1.6:1 Definition of friendship

The meanings associated with the word friend inevitably are subjective. Richardson and Ritchie (1989) suggest that friends are “people who listen, who understand, who provide the opportunity to share experiences and emotions both happy and sad” (p. 2). In addition they suggest that it is through friendships we obtain confirmation of our self-value, beliefs and identity. In varying forms their definition is mirrored by other authors (Firth and Rapley, 1990, Meill and Dallos, 1996), and is used here to reflect mainstream conceptualisation of friendship. There are various theories of how social relationships are established and maintained. What follows is a brief review of some of these theories.

1.6:2 Social Exchange Theories

The general premise of social exchange theories is that people assess relationships in light of the benefits that they may provide. They are concerned with the nature and effects of repeated exchanges within interactions, and expectations of benefits and mutual reciprocity that will be obtained. There is an economic flavour to these theories as they highlight the role of costs and rewards obtained via relationships, and the process of weighing these up to judge the overall outcome (Homans, 1950).

Thibaut and Kelley (1959) described what they referred to as the comparison level. This being the level of profit any individual comes to expect from their interactions in terms of what they think they deserve. So people with a number of successful relationships might be more demanding, whilst people with limited success in
relationship will be content with lesser rewards. The comparison level is the lowest level of outcomes that an individual will accept in light of available opportunities.

Social Penetration Theory (Altman and Taylor, 1973) emphasises how relationships develop via mutual exchanges of self-disclosure over a period of time. If one person discloses more than the other the relationship may be perceived as imbalanced and unfair. Relationships are thought to proceed to intimacy in a systematic fashion, gradually moving from superficial disclosures to more intimate, personal ones. Empirical studies have provided support for this theory (Taylor, 1968; Chaikin and Derlega, 1974).

There are inevitable risks inherent to self disclosure however. By disclosing personal information one is providing the other with power and rendering themselves vulnerable to being judged, misunderstood even rejected. Miell, Duck, and Dallos (1984) cite Yalom’s (1970) reflections on this process. Yalom (1970) discussed the degree of uncertainty involved as to the expected response and describes how individuals employ means to reduce this risk, such as obtaining information about the other person to facilitate predicting their response when one’s own information is disclosed.

1.6:3 Similarity and identity in relationships

There are other theories which focus upon how people select friends and assess how they will meet our needs. Such theories emphasise the role friendships play in confirming and validating our competence, opinions and identity. One overarching aspect of these theories is that we select friends who are similar to us as one way in which to attain assurance of our own effectiveness. One such theory is Festinger’s
(1954) social comparison theory in which other’s are used to confirm our world view, enabling us to feel validated. In selecting friends similar to ourselves or with characteristics we aspire to we are provided with a framework of how we ought to behave and what we ought to be capable of. It is suggested that mixing with people similar to ourselves facilitates communication. Duck (1973, 1977 cited in Miell, Duck and Dallos, 1984) suggested that an ultimate goal of friendships is to obtain personality support through establishing similarity. Kelly (1969) stressed the need for this to be a mutual process in which each person provides support for the others constructs of the world.

In summary, these theories suggest the importance of reciprocity in relationships, and how this may involve self-disclosure which is laden with risk and implies the need to use strategies to evaluate the outcome of disclosing. People are thought to seek out relationships with people who are similar to themselves as this facilitates confirmation of one’s own identity and validates opinions and beliefs held. And, it is suggested people select relationships in which the benefits will outweigh the costs for them.

1.6:4 Skills required for friendship
To fulfil these processes certain skills and qualities are required. In order to seek people out for friendship an individual has to have sufficient self-esteem to believe they could be liked and desired as a friend by someone else and the skills to both give and receive support within the relationship. Actively making friends implies actually ‘going’ and ‘doing’, which in turn is reliant on knowing where to go, how to get there and how to cope when you do. It is also reliant on having sufficient autonomy and power both in terms of material and interpersonal resources to be able to manage this.
Looking for identity validation implies both a need to have a sense of self and valuing this sufficiently to seek out its validation by another. Similarly if mutual self-disclosure is required then the ability to cope with taking the risk of doing this must not feel overwhelming.

If these are the skills required in developing friendships then it is arguable that people with learning disabilities are at a disadvantage because of some of the inherent difficulties they experience due to their cognitive difficulties and increased dependency needs. For example many have problems with language and communication, and their problems may mean they have less autonomy. However research cited above indicates such reasons alone are insufficient to explain away the problems they experience in making friends. Aside from the cognitive difficulties, it has been suggested above that inherent within interactions for people with learning disabilities, especially with people not similarly disabled, is the need to use strategies to manage their 'spoiled identity'. How this may affect friendship formation is discussed below.

1.7 The impact of stigma on friendship formation

1.7:1 Coping with Stigma

Taylor (1991) drew upon Goffman's (1963) writing to discuss the strategies which people with learning disabilities utilise to manage the uneasiness of interactions with people without learning disabilities. Goffman (1963) suggested that the stigmatised individual will be more familiar and adept at coping with the discomfort. Hence, Taylor (1991) argued that “the onus is thereby put upon the disabled person to cope with the able-bodied world and not the other way round” (p. 407).
As the goal for the stigmatised individual is to be accepted as 'normal', they attempt to achieve this by masking the stigmatising attribute. Goffman (1963) suggested that both 'passing' and 'covering', the techniques for managing a spoiled identity, involve judging how much information to disclose and how to manage resulting embarrassment for both parties. When the individual admits to stigma, or cannot hide it in any way, they attempt to manage any resulting tension in interaction by diverting attention away from it. Taylor (1991) suggested for people with learning disabilities this involves striving to learn communication skills that result in the stigma being as unobtrusive as possible.

1.7:2 Stigma and Social Identity

Taylor (1991) suggested that being with people who do not share a stigmatising experience affects self identity. She argued that a code of normal conduct is implicit in interaction. It can be apparent to the stigmatised person that there is a need to mask their stigma if they wish to be accepted as normal. By placing responsibility on the stigmatised person in this way the 'normal' person is able to deny any need to acknowledge how difficult it is for them to be around such 'different' people. Goffman (1963) refers to this as 'phantom acceptance'.

It is clear that attempting to manage all of these factors within a social interaction is an extremely tense and anxiety provoking process. Generally within relationship formation time is spent getting to know one another, which is largely done via exchange of personal information. This process inevitably involves the risk of being discredited and rejected as a stigmatised individual. Therefore it is suggested that attempts to control
the flow of identity information has an impact on social relationships and the development of friendships.

1.7:3 Implications

In light of what has been discussed above when considering the friendships of people with learning disabilities it is possible to hypothesise that all aspects of friendship formation are potentially difficult for them. So much of human relationships is based upon reciprocity, mutual disclosure and seeking out people who can confirm and validate identity, yet for people with learning disabilities all these aspects are loaded with complex and anxiety provoking issues related to having a stigmatised identity. These factors arguably inhibit the typical processes involved in developing friendships for people with learning disabilities.

What has been described above is how within interactions people with learning disabilities are managing through complex processes, a stigmatised identity. For people with learning disabilities the main means of communication is speech. Thus it is suggested that it is within their speech that strategies of identity management occur. It is suggested that whilst these issues are pertinent when people with learning disabilities attempt to make friends with people, they would also be relevant when they talk about their experiences of friendship. Thus it was felt that it would be appropriate to study both the content and structure of their accounts of friendship development in order to gain insight into both the nature of their experiences, and to identify when and how they used communication strategies to manage their identity and associated stigma. As a result social constructionist theories of the role of language in identity construction
were reviewed to provide a framework for developing an understanding of these issues.

1.8 Language, Social Constructionism And Discourse

According to Burr (1995) from the theoretical viewpoint of social constructionism language provides a vehicle for structuring our experience. She suggests that language makes things tangible and provides a framework within which we can make sense of our world and is not reflecting a pre-existing reality but merely providing a framework used to make sense of experience. According to social constructionist theory, language is used to 'do', to achieve something, to construct an account. Language is basically a social phenomenon (Burr, 1995) and it is within social interactions that accounts of phenomenon are constructed. One such phenomenon is identity. We construct our identity through our various interactions: therefore it is within language that identities are formed, altered and challenged. As Burr (1995) states if this is where identity is created, it should also be the focus for attaining change both personally and socially.

The meaning of a word is dependent upon the context within which it is being used. Context within this theory is referring to discourse. As Burr (1995) describes what people say is a manifestation not of their private world but of the discursive culture within which they live. Discourses are closely connected to the way in which society is organised and can be seen as reflecting what dominant beliefs are valued and what is perceived as right and wrong. An example might be that in western cultures dominant discourses reflect the value of independence as opposed to dependency. One important aspect of discourse is its challenge to the notion that reality is 'out there' waiting to be discovered. Instead it suggests that there are differing discourse available about any
phenomena but that some dominate and marginalize others. This marginalisation is achieved by discourses which uphold dominant beliefs and power relations by somehow suggesting that existent inequalities are natural. There is insufficient space here to discuss this theoretical view in depth. The important aspects of it in relation to this study are the role it ascribes to language and how it is used to construct accounts of phenomena such as ourselves, and how in turn these accounts are influenced strongly by dominant discourse which reflect current influential beliefs about the way things are or should be in any given society.

In relation to friendship, it is suggested here that mainstream definitions and theories can be considered as representative of the normative view, or mainstream discourse, of what friendships should be like and how they develop and are maintained. People with learning disabilities are also exposed to dominant discourses of the value and experience of friendship. In conjunction however they are managing their own experiences of having a stigmatised social identity, which involves striving to obscure their difference and appear 'normal'. It is suggested that this could be seen as them attempting to conform to what dominant discourse suggest is right or true. Furthermore, when considering Goffman (1963) and Taylor's (1991) work, it is argued that when constructing accounts of their friendship and attempting to conform to something of which they have different experience to that considered typical because of their stigmatised identity, they will have to rely upon strategies of identity management in order to detract from their difference and appear 'normal'. However as a result of this aspects of their experiences of impoverished social relations are masked. By attempting to understand both the nature and function of this masking, it may
become possible to gain deeper insight into the issues that make it difficult for people with learning disabilities to develop friendships.

1.9 Summary And Aims Of This Study

It has been shown that people with learning disabilities have impoverished relationships, a factor which has been linked to increased mental health problems. It has been suggested that factors such as poor social skills and lack of privacy or funds are insufficient alone to explain why there is such a vast number of isolated people with learning disabilities. Mainstream theories of friendship formation reflect the importance of mutual self-disclosure, reciprocal support and identity validation in the development of friendships. These theories implicitly reflect the psychological and pragmatic skills required to make friends with people. It is suggested that each of these aspects are complex for people with learning disabilities and in part this is because of the need for them to employ identity management strategies within social interactions. These involve monitoring the degree of identity disclosure, which in turn directly affects the typical processes of friendship formation.

Mainstream theories and definitions of friendship can arguably be viewed as representative of dominant discourse as to how friendships are developed and valued in this culture. People with learning disabilities, in their attempts to be accepted, also live under the influence of these dominant discourses and must manage the variance between these and their own experiences. However in doing this they have to employ strategies of identity management. This in turn masks some of the reality of their experiences and creates difficulty in developing a full understanding of what the issues are that make it difficult for them to build relationships.
This study aims to investigate in more detail the actual processes of friendship formation for people with learning disability. It is suggested that disclosure of personal information is anxiety laden for them, and that this would remain true also within a research interview. Thus it would not be possible or appropriate within a research project to try and get people with learning disabilities to access painful emotions associated with the experience of being labelled as having a learning disability, or the impact this has on their abilities to make friends. As a result it is felt that the most meaningful way of examining how issues of stigma impact upon friendship formation is to investigate the narratives given by people with learning disabilities by using discourse analysis. That is, to examine how they construct accounts of their relationships in terms of language and interactional skills. In conducting such an analysis it was hoped that it would be possible to reveal the nature of the management strategies they have developed, how these manifest in their interactional style and at what points these are used in the construction of their accounts. As Goffman (1963) suggested the use of these strategies to detract attention away from the stigma is a two way process which both the stigmatised and 'normal' person are involved in. Thus it was hoped that it would be possible to identify any strategies employed by the interviewer also. If such strategies, and when they were used, were identified it was hoped this would enable professional's and clinician’s to be aware during interactions with people with learning disabilities of how their speech may be facilitating them in avoiding talking about painful issues, such as those related to isolation and lack of friendship. This is not to say that having identified identity management strategies clinicians should routinely challenge their use as they arguably serve a protective function to people with learning disabilities. However, it could facilitate understanding
of what the difficult issues are and when appropriate could be commented on to enable
discussion to move to deeper levels.

In summary the aim was to address the following questions:

- how do people with learning disabilities construct accounts of friendship
  formation and experience,
- manage within their speech any variation between typical experience and their
  own, and
- what do they feel might help improve these relationships if anything.

In order to ensure that the aims were sufficiently addressed the following heuristic
questions were posed based upon mainstream theories and definitions of friendship;
they also informed the development of the interview schedule and organisation of
analysis:

- What are the meanings associated with the word friend?
- What is the importance of friendship?
- How do they get to know someone?
- How is identity, including the impact of a learning disability, managed within
  relationships?
- How close or intimate are their relationships?
- What are their perceptions of relationships being reciprocally equal?

1.9:1 Rationale for Discourse Analysis

As has been suggested above the main mode of communication for people with
learning disabilities is language, as opposed to for instance the written word or the
completion of questionnaires. It is suggested that it is within their language and speech that they construct their identity at any given moment. Furthermore, it is within such interactions that they use their language skills as a form of buffer to protect both themselves and the person they are speaking to from the distressing emotions associated with having a stigmatised identity. As Billig, (1987, 1990) has suggested one of the features of discourse analysis is its concern with rhetorical nature of speech and texts. He argues that accounts are constructed using rhetorical devices that serve a persuasive function, in that they are used to construct an argument that one’s account is reasonable. “So the analysis of rhetoric looks at the ways we use linguistic devices to present a justifiable account” (Burr, 1995, p.165.). It was felt such an analysis was appropriate to this study as the aim was to identify how both interviewer and participant used speech strategies, or rhetorical devices, to detract from the presence of a 'spoiled identity' (Goffman, 1963). By using this style of analysis it would also be possible to consider at what points in the accounts certain devices were used and therefore gain some idea as to what the deeper issues were that were more difficult to discuss. Furthermore, in view of the vulnerabilities of the client group, in terms of their levels of isolation and the possibility for them to confuse any relationship for friendship, discourse analysis seemed appropriate as it provided a means of investigating these issues without intruding upon the participants.

Using another qualitative method which did not take into account the way in which language is used to manage identity would potentially have missed useful information relevant to this study. Thus alternative qualitative methods would potentially have failed to access deeper material by not attending to the identification and function of rhetorical devices. Alternatively other methods may have reached deeper levels but
been too intrusive, or resulted in missing important material about how intrusion to deeper levels is avoided.

CHAPTER TWO - METHODOLOGY

2.0 Design

As discussed above, a qualitative design, using discourse analysis was deemed appropriate in relation to the aims of this study. Data were gathered using a semi-structured interview format and via adherence to the “Active Interviewing” model which Holstein and Gubrium (1997) propose. This model acknowledges the mutual meaning-making process which both participant and interviewer are involved in throughout the interview. The authors suggest that whilst interest remains in the content of participant responses, it is how this information is constructed in collaboration with an active interviewer that is important. They argue that it is not possible to expect answers on one occasion to be replicated on another due to differing circumstances of production. The validity of answers, according to Holstein and Gubrium (1997), does not derive from meanings held within the respondent, “but from their ability to convey situated experiential realities in terms that are locally comprehensible” (p. 117). That is, respondents’ answers are not fixed but are constructions of aspects of “reality” created in conjunction with an interviewer. This model of interviewing was deemed appropriate as it is based upon social constructionist theory and therefore relates to the theoretical roots and aims of discourse analysis and has been used in other research of this nature to good effect (Rapley, Kiernan and Antaki, 1998).
2.1 Participants

Eight adults with mild learning disabilities were recruited to the study; four men and four women. In line with Turpin et al’s (1997) guidelines, it was felt that eight participants would serve the function of the study and would be appropriate to the parameters of this project and time available. Inclusion criteria required that the participants were current users of a Community Support Service and were defined by this team as having a mild learning disability. It was also necessary that the participants could understand the rationale behind the study in order to give their informed consent to participating. For the purpose of this study the term mild learning disability was solely defined by how they were categorised by services. The rationale being that it was not the aim of this study to further define the participants, but to explore the experiences of people who had lived with the label of mild learning disability. All the participants of this study lived within an outer-London Borough.

2.2 Characteristics of Participants

To attempt to understand why people respond in a certain way it is important to understand something of the context of their lives. Below is a brief description is given of what was known by the researcher about each participant. This provides some insight for the reader as to any knowledge of the individual which may have been influential during the analysis. For reasons of confidentiality pseudonyms have been used throughout.

2.2.1 Andy

Andy was in his sixties and eight months prior to the interview had moved from a community based home which he shared with two other men with learning disabilities
to a warden protected home for older adults. He had spent the majority of his life living within institutions, and had not grown up within his family home, although had maintained contact with his family. He had been known to the Community Team since its formation when the institutions closed down. At the time of the interview he was actively involved in MENCAP.

2.2:2 Mark

Mark, was in his forties and lived in a flat located within a large block with a lady who also had learning disabilities. They were not involved in a relationship, but merely shared the living accommodation. He worked part time in a restaurant. He had been involved with the Community Support Team for a number of years, although his previous living circumstances were not known to the interviewer.

2.2:3 Paul

Paul was in his forties and had Downs Syndrome and some communication difficulties. He lived in a flat with two other gentlemen on a housing estate. He had been involved with services for many years and at the time of the interview was not working. One of the men he shared with was Tim, who also participated in the study. They had a long standing friendship. Little information about his family was known.

2.2:4 Tim

Tim was also in his forties and had Downs Syndrome. He originally came from the North of England, but had moved South some years previously as he had been known to local services for a number of years. Both he and Paul had done their independent
living training together. Tim was close to his family, although it was unclear what his previous living circumstances had been.

2.2:5 Sue

Sue was nearly forty and had Downs Syndrome. She lived alone in a community based flat. She had been due to get married some years previously but the relationship had been stopped by the family of her partner. She had regular contact with her family, and had had several jobs. At the time of the interview she was attending college.

2.2:6 Penny

Penny was in her sixties. She had also recently moved in to sheltered accommodation for the elderly. Prior to this she had lived with her mother and had had very limited experience of interacting with people outside of services or her family.

2.2:7 Karen

Karen was in her early thirties. She had recently married and lived with her husband in a flat in a housing estate. She suffered with epilepsy. Karen was one of five daughters and had regular contact with her family. She had briefly attended mainstream schooling, then boarding school for people with learning disabilities. She had then attended college and at the time of the interview was still doing so. Karen was very open about her preference for being in the company of other people with learning disabilities.
2.2:8 Ann

Ann also was in her early thirties and married. She had a son of about eighteen months. She had attended special schooling where she had been bullied. She had had a very difficult relationship with her mother, although was very close to her brother. Ann had also experienced some time living on the streets and had experienced an abusive previous relationship.

2.3 The Semi-structured Interview Schedule

A semi-structured interview was designed (Appendix two). The interview schedule was designed to address the research questions, which had emerged from the review of existing literature outlined in the proceeding section. The questions were designed as aides or prompts for the interviewer to ensure that all relevant areas of interest would be discussed during the course of the interview. To this end the questions were constructed to facilitate participants' ability to talk freely about their experiences. In order to meet the needs of the client group much attention was paid to the terminology used so that the questions were easy for the participants to understand. There was progression throughout the interview schedule towards topics that were conceptually or emotionally more demanding. Participants were encouraged to use their own language and to talk as openly as they felt appropriate about their experiences. They were also encouraged to expand on additional and related topics as they arose.

The structure and rationale for the interview is presented below.
2.3:1 Interview Schedule Structure

2.3:1.1 Section One: Meaning of Friendship

Participants were asked general questions about what the word "friend" or "friendship" meant to them. They were encouraged to state what words they might use instead of "friend". This provided information about their own language, and helped to define their understanding of what we were discussing.

2.3:1.2 Section Two: "Who are your friends?"

This section aimed to establish who the participant thought of as their friend, whether having these friends was important and whether they had ever had a best friend. This information could then be referred back to throughout the interview.

2.3:1.3 Section Three: Getting to Know People

Drawing upon Social Penetration Theory (Altman and Taylor, 1973) of friendship formation, this section aimed to enquire about the processes the individual utilised when getting to know somebody. They were asked about how they would get to know someone. Other questions in this section referred to any difficulties they experienced when trying to make friends, including the impact of having a learning disability.

2.3:1.4 Section Four: Identity In Friendship

The aim of this section was to establish, if in line with Personal Construct Theory (Kelly, 1969) and Social Identity Theory (Tajfel, 1978) they sought out friends whom they perceived as similar to themselves. The opposite was also asked, that is if they had any friends from whom they thought they were very different. In an attempt to explore their perception of self, they were asked how a friend might describe them. The
rational for posing the question in this way was derived from Kelly’s self-characterisation methodology (Kelly, 1955).

2.3:1.5 Section Five: Closeness of Friendships

Again, drawing upon Social Penetration Theories (Altman and Taylor, 1973) of self-disclosure in friendship, this section aimed to explore whether participants felt close to any of their friends, and whether they felt able to talk about private experiences and feelings and if discussing personal issues with friends was reciprocal.

2.3:1.6 Section Six: Reciprocity

Building upon the information obtained in the above section, participants were asked about whether they and their friends helped each other out, and if so how. Issues of equity in the degrees of reciprocity were explored and the participants’ feelings about any unequal relationships.

2.3:1.7 Section Seven: Help required

The final section of the interview asked participants to think of what, if anything, was missing from their friendship network, and what help they felt would be useful in addressing any difficulties they experienced in making or maintaining friendships.

2.3:1.8 Section Eight: Debriefing

Participants were asked if there was anything else they wanted to discuss that had either arisen from the interview or had not been covered during it. Throughout the interview, if difficult or emotional issues had arisen the participant was asked if they would like others involved in their care to know. This issue was raised again at the end
of each interview. Participants were then advised how they could contact the researcher again should they wish at a later date to discuss in more detail anything raised by the interview. Finally participants were asked if they would be happy if required, for the researcher to contact them again to comment on the initial findings of the study.

2.3:1.9 Section Nine: Researcher's Impressions

After each interview the researcher made notes on the emotional impact of the interview on both interviewee and interviewer, and any general impressions obtained. These were noted within the research diary (Appendix One).

2.4 Ethical Considerations

Prior to the research being undertaken, the details of the study and how all relevant ethical issues were to be addressed was presented to the local ethics committee covering the community team used for recruitment. Full ethical approval was granted on 14 October 1999 (Appendix three). The Chairman of the ethics committee was informed in writing of a subsequent alteration to the project (Appendix four).

A number of ethical issues relating to conducting research studies with people with learning disabilities have been highlighted, especially with regard to issues of consent (McCarthy, 1998; Swain, Heyman and Gillman, 1998; Stalker, 1998). Additionally, Booth (1998) discusses the ethical considerations of conducting research with lonely people. In light of this much consideration was given by the researcher to what participation may involve for the individual person, and how checks could be in place to ensure that they were able to make an informed choice about whether to take part in
the study or not. Furthermore procedures were set in place to ensure the provision of adequate debriefing and information about how to get further support if required.

A participant information and consent form (Appendix five) was presented to each participant which explained the purpose of the research and what their involvement would be if they agreed to take part. Issues pertaining to confidentiality and anonymity were explained. It was detailed verbally that any issues of concern to either the interviewer or interviewee would be discussed regarding any additional support required. It was stressed that the interview was private and that what they said would not be discussed with their support workers unless this was deemed appropriate following discussion between participant and interviewer. Participants were reassured that they could withdraw from the project at any time, or refuse to answer questions without having to give a reason. Care was taken to ensure that the language could be understood by the participants. Opportunity was provided for the potential participant to discuss their involvement in the project with either their keyworker or the Community Team Manager, who had known all participants for many years, and in the absence of the researcher. This was to facilitate potential participants speaking freely with someone who knew them well about their feelings regarding participating in order to minimise any pressure they felt under to agree to take part. On two occasions this discussion did result in the individual having no further involvement in the project.

Debriefing procedures were explicitly followed. At the end of the interview, participants were asked if they had any questions they wished to ask the interviewer, or if they wished to discuss anything further which had emerged from the interview. Any issues that had caused concern to the interviewer were also raised. On all occasions
when this occurred it was clarified by the participant that their support worker was already aware of their situation, and that they were receiving adequate support.

2.5 Procedure

2.5:1 Piloting the interview schedule

The interview schedule was initially piloted on two people without a learning disability. As a result of this process alterations to the order and wording of questions were made. The interview was then further piloted on a person with a mild learning difficulty from the community support service. In setting up the pilot interview all procedures regarding recruitment and consent were followed as outlined below. As a result of the pilot interview further alterations were made to the language used and the amount of time given within the interview to certain questions.

This pilot interview was crucial in highlighting to the interviewer some of the inherent difficulties in conducting this type of research with people with learning disabilities. It became apparent that a great deal of sensitivity needed to be given to how participants might interpret the interviewing exercise as the beginning of an on-going acquaintance, and the potential for great variation between how the interviewer and interviewee perceived the meaning of friendship. This information and insight acquired via piloting enabled the interviewer to think through if such issues should arise how they could be managed or thought about with the participants during the interviews.

2.5:2 Recruiting and Contacting Participants

Potential participants were identified by the Community Support Team manager. Either the manager, or the support worker currently involved with the identified person
was asked to make initial contact and to explain briefly the purpose of the research. Of the 11 contacted, one of which was for the pilot interview, two people declined to take part. Following this initial contact, the researcher contacted each respondent directly to arrange a time and appropriate place to meet with them to explain the research in more detail, address any questions or concerns they may have, to obtain their informed consent and to conduct the interview.

At this initial meeting the contents of the participant information sheet and consent form (Appendix five) were read through and discussed. Participants were encouraged to ask questions about the research. Following this, participants were asked to sign the consent form. Either the Service manager or Support Worker also signed the consent form as a “Witness”. The interview was then conducted. All interviews were tape recorded.

With the exception of the pilot interview, all took place within the participant’s homes. The interviews lasted between forty minutes and an hour and a half and were characterised by open rapport, which developed as the interview progressed. At the end of the interview participants were debriefed and asked if they would be happy if necessary, to be visited a second time to discuss and refine initial results. All agreed.

Following initial analysis as an aid to respondent validity (Smith, 1996) two participants were re-visited and themes identified via the analysis discussed and expanded upon.
2.6 Data Management

All the interviews were transcribed verbatim. They were then analysed using discourse analysis as outlined by Potter and Wetherell (1987). The analytic sequence is described below.

2.6:1 Immersion

The process of immersion into the data inevitably began whilst transcribing the interviews. Following this the transcripts were read and re-read many times to allow for familiarisation. During this process rough notes were made on each transcript regarding both content and process of the interview. This facilitated reflection upon how both interviewer and interviewee were active in the construction of the accounts given. Detailed notes regarding the researchers assumptions and views at this stage were entered into the research diary, along with how understanding changed and developed during the immersion process (Appendix one).

2.6:2 Coding

In order to organise a mass of data for analysis Potter and Wetherell (1987) suggest a system of coding to facilitate attending to all aspects of data relevant in answering the research questions posed.

As Seidel and Kelle, (1995) discuss the coding system in discourse analysis is not always intended as a reliable set of measures of an empirical property but represents a system of referencing the text in a way which facilitates the researcher in retrieving relevant aspects of text to the issue they are considering at any given time. Therefore
using the heuristic questions as a guide, the initial coding process focused on
categorising the content of transcripts in terms of:

- information about the meaning of friendship,
- identification of friends,
- development of friendship,
- identity in friendship,
- closeness in friendships,
- reciprocity in friendship,
- help required.

These categories represented the areas of mainstream theoretical understanding of
friendship formation being investigated: and additionally participants’ views on
assistance required. On completion of the coding process the initial coding framework
was expanded to include additional factors and processes identified within the
interactions. A worked example is included within the Appendices (Appendix six).

2.6:3 Analysis

As Potter and Wetherell (1987) state, there is no mechanical process to follow in
conducting discourse analysis but a broad theoretical framework from which to read
the text, and develop an understanding of the content and function of what was said.
They suggest that analysis evolves as the researcher attempts to make sense of the
transcripts, and identify emerging themes within them. This includes the researcher’s
reflections upon their own presuppositions about why they are reading something in a
certain way. “The basic theoretical thrust .... is the argument that peoples’ talk fulfils
many functions and has varying affects” (Potter and Wetherall, 1987, p.168). Having
identified themes and patterns the aim is to hypothesise about these functions and find linguistic evidence from the transcripts to support them.

So in this analysis, having coded the data each aspect of friendship was investigated in turn. Theoretical models of friendship were used as a working framework for comparing participants accounts of their experiences to mainstream ideas. Both similarity to and variation from mainstream theories was explored in detail with a key aspect being to try and reveal any rhetorical devices used.

As the nature of this analysis was highly subjective detailed notes of the analysis process and how the researcher’s understanding developed were entered into the research diary (Appendix one).

2.7 Validation

The type of discourse analysis used within this study had its theoretical base located within social constructionist theory, which was discussed in more detail in Section 1.8 above. In line with this theory, the underlying tenet of this study was that people construct accounts of their reality and that this is influenced by many contextual factors. It follows therefore, that different constructions of “reality” may be provided by the same person on different occasions, or to different people. Therefore there is an obvious difference within this approach as to how issues of validity are to be dealt with.

In order to address issues of validity within this study the following principles were used:
2.7:1 Auditability (Stiles, 1993)

This refers to the means by which the researcher makes the processes employed during analysis explicit to the reader. This was achieved in the following ways:

2.7:1.1 Situating the Sample (Elliott, Fischer and Rennie, 1999)

Descriptions of what the researcher knew of each of the participants are presented to the reader in order to facilitate their judgement of the range of people and situations to which the findings may be relevant.

2.7:1.2 Disclosure of Orientation (Stiles, 1993; Elliott, Fischer and Rennie, 1999)

This involves the disclosure of the researchers' expectations for the study, and preconceptions about the results, the theoretical orientation from which analysis was approached and any implicit personal values, including those held about the participants. For this study these issues were presented with the Research Diary (Appendix one).

2.7:1.3 Description of Internal Processes of Investigation (Stiles, 1993; Smith, 1996)

As with disclosure of orientation the researcher's own internal processes and developing interpretation during the analysis along with findings that were of surprise and ran contrary to initial expectations and aspects that were difficult are reflected within the Research Diary (Appendix One). Furthermore a worked example of a coded
transcript to provide some transparency to the coding process and the thinking behind this has been included within the Appendices (Appendix Six).

2.7:1.4 Providing credibility checks (Smith, 1996; Elliott, Fischer and Rennie, 1999)

Several methods for checking the credibility of the analysis were used within this study. Firstly aspects of the initial analysis were fed back to two participants (there was only sufficient time available to revisit two) for their comments. Secondly the analysis and subsequent results were looked at in detail by a supervisor with extensive experience of working with people with learning disabilities for comments and suggestions regarding alternative interpretations and possible elaborations.

2.7:2 Presentation Of Evidence (Smith, 1996)

This involves the provision of sufficient raw data to enable the reader to understand the interpretation being developed by the researcher. In this study the main themes and rhetorical devices emerging from the transcripts were demonstrated via verbatim quotes from the transcripts. In addition all complete transcripts were submitted for examination with one coded example included in the report (Appendix Six).

2.7:3 Internal Coherence (Smith, 1996)

This concept refers to whether the study presents a consistent argument and makes sense. This was addressed via consultation with the service manager of where participants were recruited from, on-going discussion with the research supervisor and attending to the links between this study and previous research.