A Portfolio of Study, Practice and Research; Submitted for The Doctorate of Psychology (PsychD) in Clinical Psychology Conversion Programme; University of Surrey.

Research Title:

'A Minority Within a Minority: Identity and Well-being Amongst Gay Men With Learning Disabilities'

Christopher Bennett,

2002
Acknowledgements

The author is indebted to all the men who so kindly and generously gave up their time to participate in the research study. Their candour and strength of spirit have been a constant source of inspiration. With special thanks to my supervisor, Dr Adrian Coyle, whose unflagging support, enthusiasm and good humour have been invaluable throughout the last three years. Thanks and gratitude must also go to Bryan Mellon both for co-facilitating the gay men’s support group with me and for all the advice and guidance he has given me. Finally, I would like to thank Rupert whose constancy and support has been inestimable.

This Portfolio is dedicated to the members of the gay men’s support group – may you each find what you are looking for.
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Introduction to the Portfolio

This portfolio contains work completed over a three-year period in fulfilment of the requirements for The Doctorate of Psychology (PsychD) in Clinical Psychology Conversion Programme. It is divided into three dossiers: professional, academic and research. In addition a copy of the candidate’s clinical psychology degree qualification and original MSc is enclosed.

The professional dossier comprises a Curriculum Vitae which gives an account of the candidate’s post-qualification experience and continuing professional development, and an evaluation of a ten week sexuality and relationship group for men with learning disabilities.

The academic dossier comprises two critical reviews of the literature. The first is entitled, ‘Difficulties in the diagnosis of Alzheimer’s disease in people with Down’s Syndrome’ and the second, ‘What evidence is there to suggest that psychoanalytic psychotherapy is an effective form of treatment for people with learning disabilities?’

The research dossier comprises a qualitative study and has employed Interpretative Phenomenological Analysis to examine the experiences of gay men with learning disabilities. It is entitled, ‘A minority within a minority: Identity and well-being amongst gay men with learning disabilities’.
Copy of Clinical Psychology Degree Qualification
UNIVERSITY OF LONDON

University College London

Christopher Jack Bennett

having completed the approved course of study and passed the examinations has this day been admitted by University College London to the University of London Degree of

MASTER OF SCIENCE

in Clinical Psychology

Provost, University College London

Vice-Chancellor

1 November 1996
Copy of Original MSc Thesis
A STUDY INTO THE ACCEPTABILITY AND EFFECTIVENESS OF INTERVENTIONS FOR CHALLENGING BEHAVIOUR IN PEOPLE WITH LEARNING DISABILITIES

CHRISTOPHER J. BENNETT

THESIS SUBMITTED IN PARTIAL FULFILMENT OF THE REQUIREMENTS OF THE MSc IN CLINICAL PSYCHOLOGY
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1996
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ABSTRACT

This study investigated community care staff's acceptability and effectiveness ratings of six commonly used interventions for treating challenging behaviour in people with learning disabilities. Case descriptions of four challenging behaviours: self-injurious behaviour, physical aggression, verbal aggression and stereotypical behaviour were given to staff followed by descriptions of six possible interventions: redirection, counselling, differential reinforcement of other behaviour, time out, medication and restraint. Staff were asked to rate each intervention for each of the four behaviours in terms of acceptability of intervention and effectiveness of intervention. This was done by using a shortened form of the 'Behavior Intervention Rating Scale'. Staff's knowledge of behavioural principles was also assessed using a shortened form of 'The Knowledge of Behavioural Principles as Applied to Children'. Factors such as job type (manager, team leader, education officer, care staff or night staff), length of experience of challenging behaviours, number of training courses attended, perceived importance of involvement in behavioural programming, actual involvement in behavioural programming and knowledge of behavioural principles were also examined to see if they influenced staff's ratings of acceptability and effectiveness of behavioural interventions.

The findings indicated that with one exception, time out, accelerative techniques (i.e. redirection, DRO and counselling) were rated as more acceptable than reductive techniques (i.e. restraint and medication). Redirection was rated as the most acceptable/effective intervention and restraint the least acceptable/effective intervention for all four challenging behaviours. Reductive techniques were rated as more acceptable
when applied to a severe behaviour (i.e. self-injurious behaviour or physical aggression) than when applied to a mild behaviour (i.e. verbal aggression and stereotypical behaviour). Acceptability and effectiveness ratings were found to be positively correlated for both accelerative and reductive interventions. Knowledge of behavioural principles was lower than expected for all job types. Actual involvement in behavioural programming was found to be negatively correlated to acceptability scores in that the more involved a staff member is in behavioural programming the less acceptable they rate behavioural interventions. These results were discussed in relation to previous acceptability/effectiveness research and implications for community services and clinical practice were highlighted.
ACKNOWLEDGEMENTS

I am very grateful to C.H.O.I.C.E. for allowing me to carry out this research project within their community homes and for their support and enthusiasm throughout the study. The importance they place on developing services for people with learning disabilities is refreshing and reassuring.

Many thanks to my supervisors Roman Raczka and Huw Williams for their constant support, encouragement and invaluable advice.

I am also extremely grateful to the home managers and all staff who took the time to participate in this study.

Finally, many thanks to Rupert whose patience and support has been greatly appreciated.
"Failure to serve people whose behaviour presents a challenge has far reaching consequences, not only for the people themselves, who may yet again find themselves excluded from their local communities, but also for the future of community based services."

(Emerson et al, 1987)

1.0 Introduction

Since the advent of community care and the gradual closure of long stay hospitals/institutions over the past two decades or so, it has become increasingly more important to find effective interventions to treat people with learning disabilities who display some form of challenging behaviour. As residents in large long stay hospitals their challenging behaviour would often have gone untreated and to some extent unnoticed by care staff. With the move into smaller community homes challenging behaviour becomes more noticeable and more of a problem as care staff attempt to follow the principles of ‘normalization’ (Wolfensberger, 1972) which suggests that people with learning disabilities become active participants in their local communities.

Any treatment for challenging behaviour needs to be effective but it must also be acceptable to the people implementing it, ie. community care staff, especially if the treatment is to be carried out successfully. It is therefore important to investigate what factors might influence care staffs' perceptions of effectiveness and social acceptability of interventions for treating challenging behaviours eg. behavioural interventions or individual psychotherapy. In this way clinicians can design interventions which are not only more effective but also acceptable to the people implementing them, which will help to increase the probability that they will be carried out consistently. In addition, investigation into this area will help to highlight possible misconceptions that care staff
have about the nature of behavioural interventions which can then be addressed in their training programme.

1.1 Challenging Behaviour and Community Services

The term ‘challenging behaviour’ came into being following an influential document by Blunden and Allen (1987), ‘Facing the Challenge’, to replace terminology such as ‘behavioural disorder’ or ‘problem behaviour’. Part of the reason for this change in terminology was to reflect the move from “deficiency” oriented language towards language that was more respectful. In addition, it implied that the challenges presented were not due to an intrinsic feature of the people displaying them but were the responsibility of the services supporting these people. Within this framework challenging behaviour can be defined as behaviour which jeopardises the individual’s quality of life and is difficult for professionals and carers to change, (Lowe and Felce, 1995). According to Emerson et al (1987), “severely challenging behaviour refers to behaviour of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit or deny access to and use of ordinary community facilities.”

The British Psychological Society’s briefing paper number three, “Services for people with learning disabilities and their carers” estimates the prevalence of learning disability in the population as one in fifty. Within this group a smaller number of people (approximately 3 - 4 per 1000 of the general population) have a severe learning disability. Within a typical district of 250,000 people this means that about 5000 people will have a learning disability, and of these 750 - 1000 people will have a severe learning disability.
It has been estimated that in the UK 10 - 15 people with a learning disability per 100,000 of the total population exhibit behaviours that present a serious challenge to services (Kieman, 1987; Lewis, Goodship, and Holden 1987). The most common forms of behaviour considered challenging are self-injury and aggression and to a lesser extent repetitive, stereotypical behaviours.

People therefore, are not intrinsically challenging, but services are challenged by various forms of behaviour. Emerson et al (1987), state that the “‘challenge’ is to overcome service inadequacies by arranging for people to be supported in the community and to establish a pattern of services that will respond effectively to their needs in the future.” If this is to be the case then it is essential that we understand what challenging behaviours represent for individuals so that a clear idea of their needs is obtained. Community services can then instigate appropriate treatment interventions.

1.2 Historical Overview and the Multi-Component Model

Not all of the behaviours labelled as challenging are specific to people with a learning disability. Behaviours such as tantrums, aggression, absconding and screaming are also common occurrences in the general population. Other behaviours such as stereotypical behaviour eg. Rocking or finger flicking, socially unacceptable and age inappropriate behaviour and the more distressing self-injurious behaviours are less common but can still be seen. A range of theories have been put forward to explain why challenging behaviour occurs. There are radical behavioural theories within which it is postulated that the behaviour is controlled by its environmental antecedents and consequences (e.g Baer, Wolf, & Risley, 1968), through to psycho-dynamic theories which postulate that the
behaviour is an attempt to alleviate guilt (e.g. Beres, 1952), or is displaced anger directed towards others (e.g. Menninger, 1935). It is likely that no one theory is sufficient to explain the range of phenomena labelled as challenging. Challenging behaviour can have a variety of aetiologies and so it is probably more helpful to look to a multi-component model for possible explanations of challenging behaviour.

A model of challenging behaviour widely accepted within the field of learning disabilities has been developed by Zarkowska and Clemments (1988). Within this model four sets of factors are considered to give rise to challenging behaviour. The first is biological and includes factors such as organic brain dysfunction, epilepsy, hearing and visual impairment and certain temperamental characteristics e.g. high intensity of emotional responding and poor adaptability to new situations. Social factors such as poor quality institutional care, being rejected by society and peers, being in environments where there are high levels of tension and interpersonal conflict and the need for consistency in management plans. Emotional factors such as a poor self concept and being overdependent on others. Finally, cognitive factors such as poor problem solving skills, poor communication skills and poor interpersonal skills. Challenging behaviour is probably a result of an interaction of several or all of these factors. Therefore, all levels need to be addressed by psychologists hoping to devise effective interventions.

1.3 The STAR Model

In an attempt to understand the meaning of challenging behaviour within a multi-component framework, Zarkowska and Clements (1988), ask the question is the behaviour a problem for the individual displaying it or for the setting in which it occurs?
They define a problem behaviour as “a complex judgement determined by the behaviour of the person, the behaviour of those around him and the beliefs, attitudes and feelings of the person making the judgement.” This definition highlights the importance of not viewing a behaviour in isolation. Environmental factors have to be taken into account as well as the attitudes of the people responding to the behaviour. As a general guideline Zarkowska and Clements state that there are five criteria which need to be met if a behaviour is to be defined as a problem:-

1) The behaviour itself or its severity is inappropriate given a person’s age and level of development.

2) The behaviour is dangerous either to the person himself or to others.

3) The behaviour constitutes a significant additional handicap for the person by interfering with the learning of new skills or by excluding the person from important learning opportunities.

4) The behaviour causes significant stress to the lives of those who live and work with the person and impairs the quality of their lives to an unreasonable degree.

5) The behaviour is contrary to social norms.

It is only when all of these factors are given consideration that effective interventions can be devised. The multi-component model states that analysis of behaviour problems has to take place at four levels:- Setting, Trigger, Actions and Results, (or STAR).

The setting refers to relatively stable features of the environment in which the behaviour occur and includes places, people times, tension in the environment, hunger etc. Trigger refers to the signals that are present within the setting which "sets off" specific behaviour e.g. someone entering the room. Action is the observable behaviour e.g. unacceptable
behaviours which need to be reduced and are: 1) determined by the setting, 2) set off by specific triggers and 3) achieve some kind of result for the individual. Results refer to the events which follow the action which may be reinforcing or punitive to the individual e.g. avoiding a task they do not want to do, or having something removed from them.

Results can be assessed through the use of a Functional Analysis. Indeed, a detailed functional analysis is crucial for an understanding of the meaning of the behaviour for an individual.

"Functional Analysis is a method of explaining a phenomenon which involves the generation of hypotheses from observable and/or unobservable data. It attempts to explain and predict the function(s) of a phenomenon through examination of the relationships that contribute to it".

( Samson & McDonnell , 1990)

The importance of this way of trying to understand behaviour is that it looks at each person's behaviour as a discrete, unique entity and tries to understand its function for this person in their environment. In this way treatment interventions can be designed which will be specific to the individual and hopefully lead to a better outcome. It is unlikely that the same challenging behaviour would be fulfilling exactly the same function for different individuals. For example in the past challenging behaviour in people with learning disabilities has often been seen as a means for seeking attention. This led to the widespread use of interventions which did not reward the person for their behaviour. Although this helped to decrease some of the "attention seeking" behaviour it did not work in many cases, eg. In some cases it increased behaviour which was being maintained by escape from social situations, (Iwata, 1987) or put the behaviour onto a
more variable reinforcement schedule.

Iwata, Dorsey, Slifer, Bauman & Richman (1985), demonstrated the range of possible functional relationships a particular challenging behaviour could have. Iwata et al studied individuals with a learning disability who engaged in self-injurious behaviour under different setting conditions. It was found that some individuals showed an increase in the frequency of their self-injurious behaviour when they were left alone which was thought to serve the function of self-stimulation, whereas others showed an increase in self-injurious behaviour when demands were placed upon them, thought to serve the function of task avoidance. For others self-injurious behaviour increased after they were given attention following a previous episode of self-injurious behaviour, perhaps a way of prolonging interaction with a staff member. As this study demonstrates the same behaviour may be precipitated and maintained by different factors for different individuals.

So, challenging behaviour can have a different meaning for different individuals. Different antecedents may trigger the behaviour and various factors may act to maintain the behaviour. It is therefore important to understand the interplay of the biological, emotional, cognitive, social and behavioural components of the behaviour through the use of the STAR approach. By using such an approach we are able to understand more fully the meaning of the individual's behaviour which is crucial to the development of effective treatment plans.
The following section will look at an applied behavioural analytic description of three specific challenging behaviours: self-injurious behaviour, verbal/physical aggression and stereotypical behaviour.

1.4 Self-injurious behaviour

According to Iwata et al (1982), self injurious behaviour is a "bizarre and often chronic form of aberrant behavior, the etiology of which is at best poorly understood". In its broadest sense self injurious behaviour can be defined as any behaviour that produces injury to the individual's own body (Tate and Baroff, 1966). The American Association of Behaviour Therapy (AABT) Task Force (1982), describes the following categories of self-injurious behaviour:–

1) Self-striking such as face slapping or head banging.
2) Biting various body parts.
3) Pinching, scratching, poking or pulling various body parts, e.g. eye poking, hair pulling.
4) Repeated vomiting or vomiting and reingesting food.
5) Consuming nonedible substances e.g. cigarettes.

Emerson (1992), puts the prevalence of self-injurious behaviour at 3 - 10% of people living in community care homes and 1 - 4% of people living independently or at home with families. For people with a profound learning disability this figure rises dramatically to 90%, (Schroeder, Schroeder, Smith & Dalldorf, 1978). There are many negative consequences for the individual who displays self-injurious behaviour. They may sustain serious physical damage such as blindness, deafness and in some extreme cases even
death. People with serious self-injurious behaviour are more difficult to place in community services and are therefore more likely to end up in an institutional setting (Laskin, Hill, Hauber, Bruininks & Heal, 1983). It has also been shown that care staff spend less time interacting with people who self-injure and that they are less likely to have structured day care activities or even treatment programmes, (Oliver, Murphy & Corbett, 1987).

1.5 Aggression (verbal and physical)

Aggressive behaviour can be in the form of verbal abuse towards others or actual bodily harm. Common forms of aggression are violence towards others and to property, explosive outbursts, temper tantrums, verbal and nonverbal threats of violence, and screaming. Eyman and Call (1977), carried out a prevalence study of aggressive behaviour amongst people with a learning disability. They found that 45% of people in institutions, 20% of people living in community services and 20% of people living with their families threatened to or actually engaged in physical violence towards other people. It has been found that aggressive behaviour is more common amongst people with less severe learning disabilities and that the behaviour is chronic and persistent. Koller, Richardson, Katz & McLaren (1983), reported that 33% of individuals studied in childhood continued to present with aggressive behaviour in adult life. As with self-injurious behaviour, aggressive behaviour has many negative consequences for the individual. It interrupts the occurrence of adaptive behaviours such as learning new skills and forming social relationships, it can lead to exclusion from community facilities such as educational placements, leisure facilities and even community placements, it can lead
to the increased likelihood of abuse from others and can lead to the individual needing long term institutional care.

1.6 Stereotypical behaviour

Stereotypical behaviours are easy to identify in that they appear unusual and bizarre and are idiosyncratic. They include such behaviours as body rocking, mouthing, complex hand and finger movements, repetitive vocalizations, gazing and repetitive behaviour patterns e.g. flicking objects. Schroeder (1970), defined stereotypical behaviour as behaviour that 1) occurs more than once, 2) involves the same topography at each occurrence, 3) has unspecified reinforcement contingencies or an unknown aetiology, and 4) is related to pathology. Eyman and Call (1977), carried out a survey involving 7,000 individuals. They found that stereotypical behaviour was present in 52% of profoundly, 34% of severely and 14% of moderate/mild learning disabled individuals. This translates to 21% of individuals living in community care homes and 17% of individuals living with their families. As with other forms of challenging behaviour, stereotypical behaviour can be detrimental to the individual. It can interfere with their learning opportunities and can reduce the opportunities for social interaction although not all researchers would agree with this view. Watkins and Konarski (1987), suggest that only individuals with severe or profound learning disabilities and high levels of stereotypical behaviour actually reduce their opportunities for learning.

Self-injury, aggression and stereotypy are the most commonly experienced forms of challenging behaviour. All present a challenge to services and in some way limit the individual’s learning opportunities and interaction with others. As well as the type of
behaviour displayed another important factor, especially in terms of devising acceptable treatment interventions is that of severity.

1.7 Severity of challenging behaviour in practice

From the descriptions appearing in the literature of challenging behaviours it appears that their effect on the individual displaying them can be variable. Some have significant consequences for the individual whereas some can be seen as having less severe consequences. Studies looking at care staffs' perception of severity of behaviour follows a similar pattern. Lowe and Felce (1995), found that behaviours which threaten the safety of the individual or other people or which cause severe social disruption are seen to be the most difficult by carers. They found that over time behaviours such as wandering away and sexual delinquency were consistently rated as a severe management problems even if the behaviours were infrequent. Aggression, temper tantrums and disturbing noises were also rated as posing severe management problems. Behaviours such as throwing objects, night disturbance, over activity and personal habits were seen as being less of a management problem even if occurring frequently. Lowe and Felce explain this by the fact that behaviours such as aggression, temper tantrums, and making noises have a direct effect on carers and constitute a problem to them, whereas behaviours such as self-isolation, inactivity, lack of responsiveness and stereotypic behaviour are inner-directed behaviour which may annoy and engender concern in carers but do not in themselves cause a great deal of disruption.
Such distinctions in severity ratings are important when looking at care staffs’ views and attitudes towards using different behavioural techniques for treating different challenging behaviours. One consideration is that care staff may be unhappy using a behavioural intervention which they see as being restrictive and punitive to the individual if the behaviour it is being employed to treat is rated as being only mildly challenging.

The following section will look at some of the more commonly used treatment interventions for the management of challenging behaviour (e.g. medication, differential reinforcement of other behaviour, redirection, physical restraint, time out), as well as a more recent approach e.g. counselling/psychotherapy.

1.8 Interventions used in the Treatment of Challenging Behaviours

1.8.1 History

Until about the 1960s it was still a commonly held belief that people with a learning disability were untreatable (Matson, 1990). This view was challenged by the advances that were being made at that time within the field of behavioural psychology and learning theory. Indeed many of the early applications of learning principles were focussed on people with a learning disability e.g. token economies, overcorrection and differential reinforcement of other behaviour (DRO). These have provided the underpinnings for treatments used today within the field of learning disabilities. Indeed, behaviour modification has become the dominant mode of treatment for people with a learning disability, (see Remington, 1991). Recent advances in treatment have been to focus on ‘self-control’ strategies where the individual is taught how to record their own target behaviour, to be more aware of times when they are becoming upset and to develop
strategies for delaying urges to self-injure or harm others (e.g. Whitman, Burgio & Johnston, 1984). Another contemporary approach is that of ‘Gentle teaching’ which has been developed by McGee et al (1987). The aim of this approach is to develop respectful and non-punitive methods for treating challenging behaviour. The approach is based upon the philosophy that everyone has an inherent longing for affection and warmth and that this longing will respond to unconditional valuing. Although based upon a novel philosophy, the techniques involved appear to be based upon traditional behavioural interventions e.g. redirection, shaping and fading and reinforcement (Jordan et al, 1989). According to Matson (1990), the major developments in behaviour modification approaches for people with a learning disability can at best be described as ‘refinement’. He gives the example of the efforts that are being made to find more socially acceptable treatments where effective but less socially acceptable alternatives are currently being used. Below are descriptions of some of the most commonly used interventions for treating challenging behaviour.

1.8.2 Differential reinforcement of other behaviour (DRO)

Differential reinforcement of other behaviour is the process whereby some non-challenging behaviours are followed by a reinforcing consequence whereas other behaviours are not. The result of this is an increase in the frequency of behaviours that are followed by the reinforcing stimulus and the gradual extinction of behaviours not followed by the reinforcing stimulus. DRO involves the reinforcement of behaviours in a specified period of time given the absence of the target behaviour (i.e. the challenging behaviour) within this time period.
1.8.3 Redirection

This procedure involves looking at and identifying the antecedents of a target behaviour. When care staff notice the occurrence of these antecedents or become aware of their possibility they try to decrease the likelihood of the target behaviour by redirecting the individual to another activity or intervene to distract the individual so that the target behaviour does not occur. In this way the antecedents to a particular challenging behaviour are minimised.

1.8.4 Time out

This is short for time out from positive reinforcement and is a form of extinction technique. The principle of time out is the withdrawal of access to reinforcement contingent on the challenging behaviour. This leads to a decrease and gradual extinction of the challenging behaviour. Time out may involve removing the individual to an unstimulating, (neutral) room for a brief period of time or may be the removal of a preferred person e.g. a carer, from the individual’s environment for a brief period of time. Birnbrauer (1976), suggested that the main effect of time-out was the disruption of an ongoing chain of inappropriate behaviour and that the effective duration of the time-out may interact with other parameters such as inhibition of responses during time-out, contingent release, and the reinforcing nature of the environment from which the individual was removed.

1.8.5 Physical restraint

Physical restraint involves using physical means to stop a person from engaging in a behaviour. This may be the use of arm splints to stop someone from hitting themselves or may involve the person being held by care staff to stop them from attacking someone else. Restraint can be noncontingent upon behaviour so that a person who frequently
engages in self-injurious behaviour might always need to wear arm splints and a protective helmet or it may be contingent upon the target behaviour. Restraint has been shown to be an effective short term measure for preventing injury to self or others but it may actually increase the likelihood of the target behaviour occurring over the longer term as the individual may become attached to the splints/helmet (Favell, McGimsey & Jones, 1978).

1.8.6 Medication

Psychiatric medication is widely used as a treatment for challenging behaviour. A study carried out by Hill, Balow & Bruininks (1985), suggested that the prevalence of use of psychiatric medication for people with challenging behaviour in America has been decreasing over the years although still remains high, 39.7% in institutions and 25.4% in community facilities. Medication continues to be prescribed for control of challenging behaviour despite little evidence that it is in fact an effective treatment. Williams, Weir, Hargrave, Parker & Marek (1984), withdrew medication from 75% of people showing self injurious behaviour over a three year period with no ill effect. In fact 80% made an improvement or remained stable. There is also the issue of side-effects both in the short term and long term. In the short term medication may make the individual confused or disoriented which can interfere with their learning opportunities and in the long term continued use of certain medication can lead to conditions such as tardive dyskinesia.
1.8.7 Counselling (psychotherapy)

It is only in the last few years that counselling has been advocated as a treatment approach for people with a learning disability. It has been presupposed that individuals should be of average or above average IQ to be able to make use of psychotherapy. However, as early as the 1970s Bicknell (1974), was advocating the use of psychotherapy for people with a learning disability stating that behaviour disturbance could be better understood by looking at the inner world of the individual. In so doing the therapist can become more aware of the person's uncommunicated needs and feelings. Rosenthal (1992), suggests that people with a learning disability may have a low self esteem, an external locus of control and an experience of learned helplessness. He recommends the use of psychotherapy to help them to develop a greater social awareness and competence, more positive self esteem and a more cohesive sense of self.

It is not just in the area of psychodynamic therapy that advances are being made in terms of treating a person with a learning disability. Lindsay, Howells & Pitcaithly (1993), have shown how cognitive therapy for depression can be successfully adapted to treat people with a learning disability and Williams and Jones (1996), discuss the use of cognitive self regulation skills where individuals with learning disabilities are taught how to identify the early signs of anxiety or anger and then to use problem solving skills to deal effectively with the situation. As behavioural treatments are turning more towards self control and regulation (e.g. Jones, Williams & Lowe, 1993), counselling/ cognitive therapy has an even greater part to play in the treatment of challenging behaviour, helping the individual to look at the possible motives and internal causes for their behaviour and to use problem solving skills to deal with these.
In practice, it is likely that a number of treatment approaches will be used in conjunction in an attempt to treat an individual’s challenging behaviour. The multi-component model would suggest that there is a need for a multi-modal approach to treatment. It is likely that care staff may have a hierarchy of techniques that they would use in responding to a challenging behaviour starting with the least restrictive/punitive, e.g. DRO or redirection, and progressing through to more restrictive interventions such as restraint should the former interventions prove to be ineffective. Counselling could be used alongside any of the above interventions with the aim of moving away from the need to use these interventions to the individual using more self regulation techniques.

There is a wide range of treatment interventions which can be employed in the management of challenging behaviours. Some of these are more restrictive to the individual than others, some may take longer than others to have an effect and with some the effects may be longer lasting than with others. An important factor in the successful implementation of treatment interventions is care staffs’ perceptions of the interventions they are using. The next section will focus on factors pertaining to care staff.

1.9 Staff behaviour and its implications for challenging behaviour

In 1993, Hastings and Remington asked the question, “Is there anything on why good behavioural programmes fail?” In this article they were questioning why behavioural interventions designed by applied behavioural analysts work very well in tightly controlled, well financed laboratory settings but so often seem to fail in the community
setting. They posited two forms of answer to this question:-

1) There are flaws in the programme itself, either in the functional analysis or in the programme design.

2) The programmes are not being implemented in an appropriate manner.

In a review of the literature they found four major factors which had been proposed as barriers to the effective implementation of behavioural programmes. These were:-

1) Aspects of services and institutions (e.g. lack of resources).

2) The nature of the programmes themselves (e.g. slow changes in behaviour).

3) Staff issues (e.g. lack of knowledge or disagreement with programme).

4) External factors (e.g. economic factors, social and legal restrictions).

Staff factors have remained poorly understood and have not been controlled for effectively in previous research. In the 1970s Reppucci and Saunders (1974), highlighted eight possible problems that confront the psychologist who attempts to implement behaviour modification in community settings. These included service related issues as well as factors pertaining to care staff. They concluded that “even after much training staff often still fail to appreciate the need for behavioural recording, viewing it instead as an unnecessary burden that must be performed in addition to their regular duties” (Reppucci & Saunders, 1974, pp 649-660). In the 1990s Donat and McKeegan (1990), continue to argue that staff may have insufficient skills or may lack the knowledge needed to carry out programmes effectively. In contrast, Bernstein and Karan (1979), argued that staff may not actually agree with the programme, finding it socially unacceptable, or feeling too protective towards the people in their care to carry out interventions which they see as being cruel or unfair.
The following sections will look in more detail at staff factors focusing on the areas of social acceptability, effectiveness, staff knowledge and training, and staff ownership/involvement.

1.9.1 Social acceptability

Social acceptability has been defined as judgements by lay persons, clients and others of whether behavioural procedures are appropriate, fair, and reasonable for the problem or client (Kazdin, 1981). There are three major factors underlying the need to investigate the acceptability of behavioural interventions. Firstly, there are often a number of different behavioural techniques which could be employed to treat the same problem. Although each of these techniques may be equally as effective as each other they may not be equally as acceptable either to the client or the people implementing them. Secondly, there are legal and ethical considerations. Budd and Baer (1976), make the point that even when a treatment intervention has been shown to be extremely effective at behaviour modification, the courts have ruled against its use as it may infringe upon client rights. Thirdly, acceptability plays an important role in the client’s reaction and response to the treatment they are receiving and to the way in which care staff implement interventions. Kazdin (1980) states that, “improving the overall acceptability may increase the likelihood that treatment is sought, initiated and adhered to once it is initiated”.

The initial work in the area of acceptability was focused around behavioural interventions used by teachers in a classroom setting (e.g. Kazdin 1980, 1981, Elliott, Witt, Galvin & Peterson, 1984; Witt, Elliott & Martens, 1984; Elliott, 1986).
The general findings of these studies were that 1) Less restrictive treatments (e.g. reinforcement based), have been rated as more acceptable than more restrictive procedures (e.g. reductive or punishment based). Miltenberger, Lennox & Erfanian (1989), describe the level of restrictiveness of a procedure as the extent to which it exerts control over the client through the application of painful, unpleasant or aversive stimuli, or the use of behaviour modifying medications. 2) All treatments have been found to be rated as more acceptable when they are applied to a severe behaviour problem than when applied to a mild problem. 3) Treatments are rated as more acceptable when they have fewer side effects and 4) treatments are rated as more acceptable when they take less time to implement.

All of these studies followed similar methodologies. The respondents, (usually college undergraduates, special needs teachers or parents), were asked to read a case description of a child who displayed some form of behavioural problem in the classroom. They were then asked to read a description usually of one intervention which might be employed to treat this problem and asked to rate it in terms of social acceptability using an assessment scale such as the ‘Treatment Evaluation Inventory’ (TEI) (Kazdin, 1980). This is a 15 item questionnaire which has been used extensively in research on social acceptability. The 15 items are rated on a 1 -7 point Lickert scale, producing a maximum acceptability score of 105. This has often be used in combination with the Semantic Differential task devised by Osgood, Succi & Tannanbaum, (1957). This consists of bipolar adjectives taken from dimensions such as evaluative (e.g. good - bad), potency (e.g. strong - weak) and activity (e.g. active- passive) and has been used to provide partial validation for the TEI as it includes an Evaluative dimension which may be related to
acceptability of treatment. Another commonly used questionnaire has been the ‘Intervention Rating Profile’ (IRP) devised by Witt and Martens (1983). This is a 20 item questionnaire. Factor analysis revealed a factor of acceptability and four secondary factors of risk, time, effects on other children and teacher skill. This will be discussed in more detail later.

There has been a number of criticisms of the acceptability research to date. Morgan (1989), argued that findings indicate that judgements of social acceptability were often related to contextual variables (e.g. severity of behaviour, and side effects), yet no study to date has looked at the role of contextual variables. Again, none of the studies have looked at the potential effects of variables such as expertise of the individual implementing the procedure, length of time an individual had experienced a problem behaviour, or duration or frequency of a procedure’s use. Criticism has also been made of the ecological validity of such analogue research. It has been asked whether judgements in analogue situations are similar to or different from those in actual treatment settings, (Reimers, Wacker & Koepppl, 1987; Witt and Robbins, 1985). To control for this, Witt and Robbins have suggested that social acceptability should be rated by treatment consumers following the actual implementation of a behavioural procedure.

Within the last few years there have been a number of studies which have investigated the acceptability of interventions used to treat people with a learning disability, (e.g. Tarnowski, Rasnake, Mulick & Kelly, 1989; Miltenberger et al 1989; Tarnowski, Mulick & Rasnake, 1990; and McDonnell, Stirmey & Dearden, 1993).
Tarnowski et al (1989), studied self-injurious behaviour using an analogue design. In this study they examined the effects of severity of behaviour (mild, moderate, severe), intervention type (positive or negative reinforcement), client status (child or adult), and setting (child or adult unit) on care staffs' ratings of acceptability. They found that 1) Accelerative techniques (i.e. DRO, DRI and stimulus control) were rated as more acceptable than reductive interventions (i.e. overcorrection, physical restraint, electric shock). 2) Acceptability ratings varied according to severity of behaviour, and 3) Client status and type of setting had no significant affect on acceptability ratings.

In their 1990 study, Tarnowski et al replicated this study but in a behavioural treatment setting. Once again they found that accelerative techniques were rated as more acceptable than reductive techniques but this time there was no significant effect of severity of behaviour on acceptability ratings. They did find though that in general, behavioural interventions were rated as more acceptable by staff working in a behavioural treatment setting as compared to their previous study which was conducted in a developmental treatment setting.

Miltenberger et al. (1989), studied the acceptability of four behaviour modification procedures, (DRO, time-out, overcorrection and contingent shock) as applied to a severe and mild behaviour problem. In this study the raters were either supervisory or direct care staff from either a community based setting or an institutional setting. Results showed that treatments were rated according to their restrictiveness i.e. DRO was rated most acceptable followed by time-out, overcorrection and finally shock. There was a treatment by problem severity interaction, with community staff rating DRO as more
acceptable for mild problems and institutional staff rating shock as more acceptable for severe problems. The results also suggested that institutional staff favoured restrictive procedures more so than community staff. There were no differences found between acceptability ratings of direct care staff or supervisory staff in either setting.

McDonnell et al's 1993 study investigated undergraduates' and teenagers' acceptability ratings of two methods for physical restraint, either on the ground or in a chair. Both groups rated the chair method as a more acceptable form of restraint than on the ground. This study used a novel methodology in that respondents were shown video recordings of care staff role playing a restraint situation. McDonnell et al suggest that this approach models more accurately the methods of physical restraint used by carers in day to day situations, and that seeing a procedure may be a better analogue than reading about it.

As the findings from these studies indicate, research into the acceptability of behavioural interventions for treating challenging behaviour has not always agreed. One consistent finding is that interventions are rated for acceptability in terms of their restrictiveness, i.e. the most restrictive interventions such as restraint and electric shock are rated as less acceptable than DRO and stimulus control. However the findings have been inconsistent for factors such as the severity of the challenging behaviour and the type of setting where the study was carried out.
1.9.2 Effectiveness

The concepts of effectiveness and acceptability appear to be closely related although this is not a straightforward relationship. Von Brock and Elliott (1987), state that an effective treatment is one that changes a problem in the desired direction. Unlike effectiveness acceptability does not necessarily depend on outcome. Indeed an acceptable treatment may be one that is totally ineffective. In the same way an effective intervention may be one that is totally unacceptable. In general, if a treatment is seen as being effective, it is more likely to find favour and be used appropriately, thereby having a positive outcome.

Witt and Elliott (1985), propose a reciprocal relationship between acceptability and effectiveness i.e. theoretically, treatments that have been shown to work will be more acceptable to those who use them, and the more acceptable a treatment is perceived to be, the more effective it is likely to be, as a result of factors such as treatment compliance and integrity.

Research investigating this reciprocal relationship has provided conflicting results. Kazdin (1981), found no relationship between efficacy and acceptability. However, this study has been criticized for having methodological flaws, (McMahon & Forehand, 1983; Witt, Elliott & Martens, 1984), such as using too narrow a range of effect strength which may account for the lack of relationship. Other studies have found a positive relationship between effectiveness and acceptability. Clark and Elliott (1987), found that when respondents understand an intervention, treatments described as strong and successful were rated as more acceptable than those described as weak and not so successful. Von
Brock and Elliott (1987), gave particular attention to the relationship between these two concepts. In their study teachers were asked to rate acceptability of one of three different classroom interventions, token economy, response cost, or time-out. To help them do this they were given information about the effectiveness of the different interventions, (either consumer satisfaction information or research based outcome information). Results showed an interaction between problem severity and effectiveness information i.e. with a mild problem, research based outcome information increased acceptability ratings more than if no effectiveness information was given. They conclude that teachers perhaps feel more able to deal with milder problems and so are more open to suggestions about treatments and information regarding these treatments. Furthermore, Von Brock and Elliott found acceptability and effectiveness to be highly correlated although two distinct concepts. The study utilized the ‘Behaviour Intervention rating Scale’ (BIRS) (Elliott and Von Brock, 1991), which builds upon an existing measure of acceptability by adding nine new items which relate to effectiveness. These items were derived from the literature on effectiveness research and include such things as:-

- Soon after using the intervention, the teacher would notice a positive change in the problem behaviour.

- The intervention would produce a lasting improvement in the child’s behaviour.

- The intervention should produce enough improvement in the child’s behaviour so the behaviour no longer is a problem in the classroom.

1.9.3 Staff knowledge and training

One factor which can lead to poor acceptability ratings for behavioural techniques and even to the breakdown of behavioural programmes is that care staff may not have the knowledge or training necessary to carry out behavioural interventions effectively.
Gardner and Cole (1987), state that staff responsible for treatment programming frequently do not have a level of training and competence in behavioural principles that is necessary to develop, implement, and supervise quality therapeutic treatment plans, especially for persons with complex clinical problems. To look at the behavioural knowledge among direct care staff in an inpatient psychiatric unit Donat and McKeegan (1990), utilized the 'Inventory of behavioural knowledge' questionnaire (McKeegan & Donat, 1988), which is a 44 item questionnaire presented in multiple choice format. They found that there was a strong association between level of education and behavioural knowledge. Disciplines with a professional training least related to the mental health field (e.g. registered nurses and psychiatric aides), performed relatively poorly. They note that these are the professionals who are most likely to be the ones who implement behavioural programmes. They concluded that there is a desperate need for further training for staff who have to implement behavioural treatments.

Similar results were found by Aitken et al (1993), studying behavioural knowledge amongst care staff who work with people with a learning disability. They found that managerial and therapist staff tended to perform better on the questionnaire than direct care staff. Academic level was also found to be significantly correlated with total score. Surprisingly, they found that length of employment and length of time since formal training in the application of behavioural techniques were not significantly related to performance on the questionnaire. They also found that self perceived competency was not related to performance on the questionnaire. This means that selection for training courses should not necessarily rely on self perceived competency in the use of behavioural techniques. It must be remembered when examining the literature on staff
knowledge that low levels of knowledge on a questionnaire may not necessarily predict an individual’s skill at using behavioural techniques. Donat and McKeegan (1990), conclude that further research using direct observation is required to investigate the strength of relationship between level of knowledge as assessed by a questionnaire and staff implementation of behavioural techniques in the workplace.

It is therefore not surprising that staff training is needed in services for people with a learning disability. Indeed, it seems that most care staff have had no formal preparation for a job working with people who display challenging behaviours in terms of relevant educational and training experiences and moreover the skills required by direct care staff are frequently changing as behavioural techniques are refined and developed, (see Reid and Green, 1990).

Donat, McKeegan & Neal (1991), developed and evaluated a training programme to increase the knowledge and skill of direct care staff in the application of behavioural methods in a psychiatric hospital. This consisted of a two day workshop focusing on methods to accurately identify behaviours, pinpointing possible antecedents, developing contingency management procedures, identifying positive reinforcers, utilizing least restrictive methods of behavioural management and noting the importance of staff behaviour in influencing patient behaviour. The ‘Knowledge of Behavioral Methods Inventory’ (McKeegan and Donat, 1988), was used to evaluate the effectiveness of the course. They found that differences in staffs’ levels of knowledge which existed prior to the training programme (as found in the earlier literature), disappeared as a result of the training programme.
It therefore seems highly likely that care staff do not have a detailed enough knowledge of the behavioural principles behind the interventions they are being asked to implement. This may mean that interventions are not being carried out appropriately or effectively. There is a great need for the behavioural knowledge of all staff to be assessed so that training courses can be devised to fill the gaps in staff's knowledge. It may also be the case that staff rate behavioural interventions as more or less acceptable depending on their level of knowledge of behavioural principles.

1.9.4 Staff ownership of and involvement in behavioural programmes

It has long been known in the field of organizational psychology that the more involved and motivated an employee is in his/her workplace the better their job performance will be. As early as 1912 Webb stated that ownership creates a sense of “shared responsibility” and “common interest” and leads to “zeal and careful working”. Campbell and Pritchard (1976), stated that job performance is an interactive effect of aptitude level, skill level underlying the task, choice of degrees of effort to expend and to persist and of facilitating and inhibiting conditions not under the control of the individual. To date there is a dearth of research on the effects of ownership, involvement and motivation on care staffs’ job performance. There is no apparent reason why care staff as well as industrial workers should not be influenced by these factors.

The organizational literature defines employee ownership in terms of three basic fundamental rights:- 1) the right to possession of some share of the owned object’s physical being and/or financial value, 2) the right to exercise influence (control) over the owned object and 3) the right to information about the status of that which is owned.
Although ownership of behavioural programmes does not fit neatly into this model comparisons can be made. Care staff could be involved in the decision making process of behavioural programming and be able to express their views about the nature of the programme etc. They could be kept informed of the progress of the programme from the clinical psychologist’s and managerial staffs’ perspective. Although there are no financial rewards to be gained from ownership of behavioural programmes there are perhaps psychological rewards e.g. knowing they are involved in decreasing an individual’s challenging behaviour and therefore maximizing their learning opportunities, a sense of having something valuable to contribute to the decision making process and of having their views heard.

Other consequences have been noted following employee ownership for example increased levels of job commitment and increased productivity and less absenteeism. In a recent study Mishra and Gupta (1994), looked at the effects of motivation and job involvement on the performance of blue-collar workers. They found that motivation and involvement were both significantly related to performance.

Based upon these findings it can be hypothesised that care staff who feel more involved in the planning and monitoring of behavioural programmes will be more motivated to carry these out consistently and will be more likely to perceive behavioural interventions as acceptable and effective for use with people with learning disabilities.
2.0 Summary

Community services are now having to meet the demands of providing care and services to people with a wide range of challenging behaviour. Procedures such as functional analysis and theories such as the multi-component model expressed in terms of STAR enable psychologists and care staff to understand the meaning of certain behaviours to the individual and provide a basis for treatment interventions. There are currently a wide range of effective treatment approaches available to the psychologist ranging from behavioural techniques through to counselling and psychotherapy. Despite research highlighting the efficacy of behavioural programmes their success rate in community settings is often low. There have been a number of theories put forward to account for this e.g. care staff do not perceive the interventions to be socially acceptable or effective and staff may have a limited knowledge of the behavioural techniques they are being asked to implement. Another aspect, not previously researched, is the degree to which care staff feel themselves to be involved in the decision making process.
3.0 Aims of this study

According to Hastings and Remington (1994), "there is as yet little or no direct evidence about how, when and why staff follow, (or fail to follow) behavioural programmes". The present study aims to explore further community care staff's ratings of acceptability and effectiveness of different interventions used to respond to challenging behaviour in people with learning disabilities and the possible factors which might influence these ratings, e.g. job title, length of experience, knowledge of behavioural principles, number of training courses attended and degree of involvement in behavioural programming.

Previous research has been limited (in terms of validity and generalizability of results) by use of analogue material, (see Reimers et al, 1987; Witt and Robbins, 1985 and McDonnell et al, 1993). The present study aims to increase the ecological validity of the research by basing the case descriptions of the challenging behaviours on actual examples of behaviour experienced in the community homes where the study is to be carried out. The interventions were chosen as they are also commonly employed in these community homes. In this way all staff should have first hand experience of the challenging behaviours and interventions used in this study. This means that staff should be able to use their own experience of both the behaviours and interventions when making their responses.

3.1 Type of intervention

The existing literature suggests that overall, accelerative techniques (e.g. DRO and redirection) are rated as being more acceptable than reductive techniques (e.g restraint,
time out and medication). In the present study care staff will be asked to rate in terms of acceptability and effectiveness four commonly used interventions for treating challenging behaviour: - differential reinforcement of other behaviour, time out from positive reinforcement, medication, and physical restraint. Within the field of learning disabilities these interventions have previously been investigated by Tarnowski et al (1989, 1990) and Miltenberger et al (1989). The present study aims to replicate previous findings within the area of adults with a learning disability and challenging behaviour.

The present study aims to expand upon these findings by including two further interventions: - counselling and redirection. Redirection, although a commonly used intervention, has not previously been investigated and counselling has only recently been used as a treatment approach for people with a learning disability and has therefore not been included in previous research. It is hypothesised that both counselling and redirection will be perceived as acceptable interventions and will be rated as more acceptable than physical restraint, time out, and medication. It is hypothesised that there will be no significant difference between acceptability ratings for counselling, redirection and differential reinforcement of other behaviour.

3.2 Perceived Effectiveness

Although the literature on acceptability of classroom behavioural interventions has examined the perceived effectiveness of these interventions (e.g. Von Brock and Elliott, 1987; Clark and Elliott, 1987), perceived effectiveness of interventions used for challenging behaviours has not previously been investigated. Although Von Brock and Elliott (1987) found a positive correlation between acceptability and perceived
effectiveness, other researchers (e.g. Kazdin, 1981), did not. It is hypothesised that there will be a positive correlation between acceptability and effectiveness for accelerative techniques but that there will be no correlation between these two concepts for reductive techniques i.e. the intervention may be perceived as being effective but would not be rated as acceptable.

3.3 Type of Challenging Behaviour

Previous research in this area (e.g. Tarnowski et al, 1989, 1990; Miltenberger et al, 1989; & McDonnell et al, 1993) has focused on one or two types of challenging behaviour, usually self-injurious behaviour and aggression. This study aims to expand upon these findings by including a range of challenging behaviours that care staff would be exposed to in a community setting i.e. self-injurious behaviour, physical aggression towards others, verbal aggression and stereotypical behaviour.

3.4 Problem x Intervention Match

This study aims to investigate whether certain interventions are perceived as more acceptable and effective for certain challenging behaviours. The previous literature has been divided as to whether acceptability ratings vary as a function of severity of behaviour. It is expected in this study that restrictive/reductive interventions will be rated as both more acceptable and effective for more severe challenging behaviour whereas accelerative interventions will be viewed as more acceptable and effective for less severe behaviours, (in this context severity will be defined according to the findings of Lowe and Felce, 1995). It may also be the case that reductive interventions will be seen as being effective for less severe behaviour problems but would not be viewed as acceptable.
3.5 Staff Variables

This study aims to look at the effect of care staff variables i.e. level of knowledge of behavioural principles, length of experience, number of relevant training courses attended, job level (care staff, manager etc.) and sense of involvement in behavioural programming on ratings of acceptability and effectiveness. As in previous research into level of knowledge (e.g. Donat and Keegan 1990, Aitken et al 1993) it is anticipated that people with more experience and who have been on more training courses will have higher levels of knowledge of behavioural principles. Miltenberger et al’s findings suggest that job type has no effect on acceptability ratings. This study intends to re-examine this finding. It is anticipated that supervisory staff and managers will rate behavioural interventions overall as more acceptable than direct care staff. It is also anticipated that all staff will rate that it is important for them to be involved in behavioural programming but that managers will actually be more involved in behavioural programming than other job types. It is expected that people with more experience, people who have been on more training courses, people with a higher level of knowledge and those with an increased sense of involvement of behavioural programmes will rate behavioural interventions as more acceptable and effective.
3.6 Summary of hypotheses

1) Acceptability and effectiveness:

I. Accelerative techniques will be rated as more acceptable than reductive techniques.

ii. Acceptability and effectiveness will be positively correlated for accelerative techniques but not for reductive techniques.

iii. There will be a problem x interaction match i.e. certain interventions will be rated as more acceptable/effective for certain problem behaviours. This will be influenced by severity of the behaviour.

2) Staff Variables:

I. Knowledge will vary as a function of experience, job title and number of training courses attended.

ii. Acceptability ratings will vary as a function of job type, length of experience, number of training courses attended, knowledge of behavioural principles and involvement in behavioural programming.
4.0 METHODOLOGY

4.1 Participants

Seventy three members of staff from six community care homes for people with learning disabilities and challenging behaviours participated in this study. The care homes are based in Berkshire and are owned by a company called C.H.O.I.C.E (Community Homes of Intensive Care and Education). Participation in the study was voluntary although staff were given time during their working day to complete the questionnaires. One hundred and sixteen staff were sent questionnaires, of these 73 returned completed questionnaires. This represents a 63% response rate. Of the 73 completed questionnaires, 38 were from direct care staff, 6 from team leaders, 6 from education officers, 12 from night staff and 11 from managers, (this includes deputy managers). Twenty four of the questionnaires were completed by male staff and 49 by female staff. The mean length of experience of working with people with challenging behaviours was five years 1 month (S.D = 5.1, range = 0 years - 20 years). The mean number of relevant training courses attended was 5.1 (S.D = 4.4, range = 0 - 20).

4.2 Design

This study employed a correlational design in the form of a survey and used measures of acceptability and perceived effectiveness of interventions, knowledge of behavioural principles and involvement in behavioural programming as described below.
4.3 Measures

4.3.1 ‘The Knowledge of Behavioural Principles As applied to Children’ (KBPAC)

This instrument was devised by O’Dell, Tarler-Benlolo and Flynn, (1979) and is a 50-item multiple choice test designed to assess understanding of the application of basic behavioural principles with children. This questionnaire presents problem situations to which the respondent has to select the response which has the greatest probability of producing the desired effect. Issues included in the questionnaire include basic behavioural assumptions about behavioural change, principles of reinforcement and punishment, schedules, shaping, monitoring, differential attention and extinction. As this instrument takes between 30 - 60 mins to complete it was shortened to 14 items (appendix two), which were thought to be the most relevant to a learning disabilities population according to three clinical psychologists who work in this area. The wording of the test items were altered slightly to make them applicable to a learning disabilities population i.e:-

*The first step in changing a problem behaviour is to:*

a) Reward the person when they are behaving nicely.
b) Punish the person for misbehaviour.
c) Carefully observe the behaviour.
d) Seek help from a psychologist.

4.3.2 ‘Behavior Intervention Rating Scale’ (BIRS)

This scale was devised by Elliott and Von Brock Treuting (1991) and has been modified in the present study to obtain a measure of acceptability and effectiveness. This instrument is a revision and extension of the ‘Intervention Rating Profile’ (IRP-15) (Martens et al 1985), which is a 15 item single factor scale that has been demonstrated to assess treatment acceptability. This has a Cronbach’s alpha of .98. The BIRS was
developed by adding nine new items to the IRP-15 relating to effectiveness and time. The 24 item BIRS is scaled on a 6 point Likert format ranging from *Strongly disagree* to *Strongly agree*. This has an alpha coefficient of .97 and the three factors of Acceptability, Effectiveness and Time have alpha coefficients of .97, .92, and .87 respectively. Again for the sake of brevity the BIRS was shortened to three items only and the wording changed to make it applicable to a learning disabilities population e.g.-

**Sample item from the shortened BIRS**

* I would be willing to use this intervention with the residents in my home with similar problems.

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Not sure</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disagree</td>
<td>either way</td>
<td>Agree</td>
</tr>
</tbody>
</table>

* This intervention would be effective in this situation and in other situations.

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Not sure</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disagree</td>
<td>either way</td>
<td>Agree</td>
</tr>
</tbody>
</table>

* This intervention would quickly have an effect on the client’s behaviour.

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Not sure</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disagree</td>
<td>either way</td>
<td>Agree</td>
</tr>
</tbody>
</table>

These are the most representative items for each factor and have factor loadings of .83, .78, and .82 respectively.

**4.3.3 Staff Involvement Measure**

Staff involvement in behavioural programmes was obtained by asking staff to rate from 1 - 10 firstly how involved they were in the planning and running of behavioural procedures and secondly how important they thought it was that they were involved in
the planning and running of behavioural procedures in their home.

4.4 Case Descriptions

The case descriptions used were similar in style to those used in the previous research on acceptability and effectiveness, (shown in full in appendix 3). Descriptions of the four different types of challenging behaviour were given e.g.

**Example of Case Description**

"Angus is a 25 year old man with a severe learning disability who is resident in a community house. At times Angus will become verbally abusive to people around him. This will take the form of swearing at them, threatening them e.g.: "I’m going to beat you up", and occasionally spitting at them. He has never been physically abusive towards anybody."

These were based upon actual examples of challenging behaviour experienced in the community homes and were obtained by looking at behavioural programmes in operation in the homes. By doing this it was hoped that all of the participants would have had direct experience of the types of behaviours described. In the same way the interventions were also based upon actual procedures in operation in the community homes to maximize the likelihood that respondents would have experience of the intervention described. The descriptions of the six interventions follow on from the descriptions of each of the problem behaviours e.g:-

**Example of Intervention**

If Angus is not verbally abusive for a specified period of time he is given a small reward such as listening to a song that he likes and is praised by staff. If he is verbally abusive during this time the reward is put off for a period of time.
4.5 Procedure

Ethical approval for this study was obtained from the company’s ethics committee (see appendix 1). The rationale for the research was discussed with each of the home managers so that they could give a brief description of the study to their staff. Managers were then given two questionnaires for each member of staff and for themselves i.e. the shortened version of the ‘KBPAC’ and the descriptions of problem behaviours and interventions including the shortened BIRS. These were distributed to staff during their monthly staff meeting and they were asked to complete them and return them in a sealed envelope marked confidential within two weeks. Written instructions for how to complete the questionnaires were given. All staff were assured of confidentiality and participation was entirely voluntarily.

Demographic information about each staff member e.g. length of employment and number of training courses attended, was obtained from records held by the company’s training coordinator.
5.0 RESULTS

5.1 Acceptability of Interventions

To examine the acceptability ratings of the six interventions for each of the four types of problem behaviour a 2 (problem severity) x 2 (problem type) x 6 (intervention type) repeated measures ANOVA was carried out (see table one).

There was a significant main effect for severity, $F = 60.58$ $p<.001$, indicating that certain interventions were rated as more acceptable for high severity problems (i.e. self-injurious behaviour and physical aggression), than low severity problems (i.e. verbal aggression and stereotypical behaviour). There was a significant interaction between severity and intervention, $F = 61.77$ $p<.001$, indicating that acceptability ratings for interventions varied as a function of the severity of the problem behaviour. A main effect was found for problem, $F = 25.04$ $p<.001$, meaning that acceptability ratings for interventions varied significantly between the four problem behaviours. A main effect was found for intervention, $F = 30.00$ $p<.001$, indicating that some interventions were rated as more acceptable than others and a significant interaction between problem and intervention, $F = 21.99$ $p<.001$, indicates that people rated interventions differently according to the problem they were being used to treat. The significant interaction between severity and problem, $F = 37.58$ $p<.001$, indicates that people varied their acceptability ratings for interventions depending on which severity level (i.e. high or low) the problem came under.
**Table 1 Analysis of Variance for Severity, Problem and Intervention**

<table>
<thead>
<tr>
<th></th>
<th>SS</th>
<th>DF</th>
<th>MS</th>
<th>F</th>
<th>SIG</th>
</tr>
</thead>
<tbody>
<tr>
<td>Severity</td>
<td>946.89</td>
<td>1</td>
<td>946.89</td>
<td>60.58</td>
<td>.001</td>
</tr>
<tr>
<td>Problem</td>
<td>227.26</td>
<td>1</td>
<td>227.26</td>
<td>25.04</td>
<td>.001</td>
</tr>
<tr>
<td>Intervention</td>
<td>3635.64</td>
<td>5</td>
<td>727.13</td>
<td>30.00</td>
<td>.001</td>
</tr>
<tr>
<td>Sev x Prob</td>
<td>589.19</td>
<td>1</td>
<td>589.19</td>
<td>37.58</td>
<td>.001</td>
</tr>
<tr>
<td>Sev x Int</td>
<td>3499.51</td>
<td>5</td>
<td>699.90</td>
<td>61.77</td>
<td>.001</td>
</tr>
<tr>
<td>Prob x Int</td>
<td>11173.74</td>
<td>5</td>
<td>234.75</td>
<td>21.99</td>
<td>.001</td>
</tr>
<tr>
<td>Sev x Prob x Int</td>
<td>1693.29</td>
<td>5</td>
<td>338.66</td>
<td>32.08</td>
<td>.001</td>
</tr>
</tbody>
</table>

**Table 2 Mean Scores for Interventions at High & Low Severity Levels**

<table>
<thead>
<tr>
<th>Intervention</th>
<th>High Severity (total scores)</th>
<th>Low Severity (total scores)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Restraint</td>
<td>-1.54</td>
<td>-9.2</td>
</tr>
<tr>
<td>Medication</td>
<td>5.38</td>
<td>-1.37</td>
</tr>
<tr>
<td>Time Out</td>
<td>7.53</td>
<td>0.00</td>
</tr>
<tr>
<td>DRO</td>
<td>3.28</td>
<td>1.63</td>
</tr>
<tr>
<td>Redirection</td>
<td>9.45</td>
<td>7.61</td>
</tr>
<tr>
<td>Counselling</td>
<td>4.94</td>
<td>3.33</td>
</tr>
</tbody>
</table>
Figure 1 Mean Acceptability Scores for Interventions at High & Low severity

Levels

![Bar chart showing mean acceptability scores for interventions at high and low severity.]

Figure 2 Mean Acceptability Scores for Interventions Overall

![Bar chart showing mean acceptability scores for interventions overall.]

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In table 2 the mean acceptability scores for each intervention for both high and low severity behaviours are shown, (this is also shown in figure 1). This indicates that for high severity behaviours redirection is rated as the most acceptable intervention followed by time out, medication, counselling, DRO and finally restraint. For low severity behaviours redirection is again rated as the most acceptable intervention followed by counselling, DRO, time out, medication and finally restraint.

Looking further at the significant main effect for intervention, table 3 and figure 2 give the overall mean acceptability scores for each of the six interventions. The mean scores indicate that overall the order of interventions from most acceptable to least acceptable is:- 1) redirection, 2) counselling, 3) time out, 4) differential reinforcement of other behaviour (DRO), 5) medication and 6) restraint. A series of related samples T-test analyses were conducted to test for significant differences between individual intervention types (see table 4).

The results indicated that scores for redirection are significantly different from all other interventions at the .05 level of significance except for time out. Counselling is significantly more acceptable than DRO and restraint but not time out or medication. Time out is significantly more acceptable than restraint as is DRO and medication. DRO is not rated as significantly more acceptable than medication. Restraint is rated as the least acceptable technique overall.
Table 3 Mean Acceptability Scores for the Six Interventions Overall

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Restraint</td>
<td>-2.68</td>
<td>1.98</td>
</tr>
<tr>
<td>Medication</td>
<td>1.00</td>
<td>2.01</td>
</tr>
<tr>
<td>DRO</td>
<td>1.23</td>
<td>.61</td>
</tr>
<tr>
<td>Time Out</td>
<td>1.87</td>
<td>2.37</td>
</tr>
<tr>
<td>Counselling</td>
<td>2.07</td>
<td>.47</td>
</tr>
<tr>
<td>Redirection</td>
<td>4.27</td>
<td>.65</td>
</tr>
</tbody>
</table>

Table 4 T-Values for Paired Differences Between Each Intervention

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Counselling</th>
<th>Time Out</th>
<th>DRO</th>
<th>Medication</th>
<th>Restraint</th>
</tr>
</thead>
<tbody>
<tr>
<td>Redirection</td>
<td>-14.43*</td>
<td>2.40</td>
<td>-16.25*</td>
<td>-3.99*</td>
<td>8.25*</td>
</tr>
<tr>
<td>Counselling</td>
<td>.17</td>
<td>6.23*</td>
<td>1.16</td>
<td>5.35*</td>
<td></td>
</tr>
<tr>
<td>Time Out</td>
<td>-.60</td>
<td>-2.29</td>
<td>-8.40*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DRO</td>
<td>.24</td>
<td></td>
<td>4.45*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medication</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>8.03*</td>
</tr>
</tbody>
</table>

(* indicates significance at the .05 level)
5.2 Problem x Intervention Match

The significant interaction between problem and intervention indicates that different interventions are rated as more or less acceptable depending on the problem behaviour they are being used to treat. To see what interventions were rated as most and least acceptable for each type of problem (i.e. self-injurious behaviour, physical aggression, verbal aggression and stereotypic behaviour), the mean scores for the six interventions for each problem behaviour were compared. This is summarized in figure 3, (see also appendix 4) and suggests that overall redirection is rated as the most acceptable intervention and restraint the least acceptable intervention for all four problem behaviours. Figure 3 also shows the significant interaction between severity and intervention in that for severe behaviours (i.e. self-injurious behaviour and physical aggression), time out is rated as second most acceptable intervention after redirection but for less severe behaviours (i.e. verbal aggression and stereotypic behaviour), counselling is rated as second most acceptable intervention. Again, in terms of least acceptable interventions, for severe behaviour problems DRO is rated as second least acceptable intervention following restraint compared to medication for less severe behaviours.

Four related samples T-tests were conducted to compare redirection mean scores with mean scores for all other interventions for each type of challenging behaviour. This is summarized in table 5. This shows that for self-injurious behaviour, verbal aggression and stereotypical behaviour redirection was rated as significantly more acceptable than all other interventions. However, for physical aggression redirection is rated as significantly more acceptable than time out, DRO and restraint but not medication ($t = 1.02$), or counselling ($t = 1.87$).
Figure 3 Mean Acceptability Scores for each Intervention for all four Challenging Behaviours
Table 5 Results of Related Samples T-Tests between Redirection and all Other Interventions for Each Type of Problem Behaviour

<table>
<thead>
<tr>
<th></th>
<th>Time Out</th>
<th>Medication</th>
<th>Counselling</th>
<th>DRO</th>
<th>Restraint</th>
</tr>
</thead>
<tbody>
<tr>
<td>Redirection</td>
<td>-0.65*</td>
<td>2.97*</td>
<td>7.30*</td>
<td>-7.55*</td>
<td>-10.12*</td>
</tr>
</tbody>
</table>

Self-injurious behaviour
(* indicates significance at the .05 level)

<table>
<thead>
<tr>
<th></th>
<th>Time Out</th>
<th>Medication</th>
<th>Counselling</th>
<th>DRO</th>
<th>Restraint</th>
</tr>
</thead>
<tbody>
<tr>
<td>Redirection</td>
<td>-2.77*</td>
<td>1.02</td>
<td>1.87</td>
<td>3.67*</td>
<td>4.47*</td>
</tr>
</tbody>
</table>

Physical aggression

<table>
<thead>
<tr>
<th></th>
<th>Counselling</th>
<th>Time Out</th>
<th>DRO</th>
<th>Medication</th>
<th>Restraint</th>
</tr>
</thead>
<tbody>
<tr>
<td>Redirection</td>
<td>-3.14*</td>
<td>-2.82*</td>
<td>-4.6*</td>
<td>-5.24*</td>
<td>-12.16*</td>
</tr>
</tbody>
</table>

Verbal aggression

<table>
<thead>
<tr>
<th></th>
<th>Counselling</th>
<th>DRO</th>
<th>Time Out</th>
<th>Medication</th>
<th>Restraint</th>
</tr>
</thead>
<tbody>
<tr>
<td>Redirection</td>
<td>-6.26*</td>
<td>8.09*</td>
<td>10.11*</td>
<td>9.96*</td>
<td>15.58*</td>
</tr>
</tbody>
</table>

Stereotypical behaviour
5.3 Effectiveness and Acceptability

A Pearson product moment correlation was carried out to look for a correlation between acceptability ratings and effectiveness ratings for both accelerative techniques (i.e. redirection, DRO and counselling) and reductive techniques (i.e. restraint, medication and time out). For accelerative techniques there was a significant correlation between acceptability and effectiveness, \( r = .62 \quad p < .001 \), indicating that interventions rated as acceptable were also rated as effective. For reductive techniques there was also a positive correlation between acceptability ratings and effectiveness ratings, \( r = .49 \quad p < .001 \), indicating that reductive techniques rated as effective were also seen to be acceptable.

5.4 Knowledge

Mean scores obtained by each job type (i.e. care staff, night staff, team leaders, education officers and managers) on the knowledge questionnaire are shown in table 6 and again in figure 4.

Mean scores for each group were compared by analysis of variance to see if there were significant differences between the scores. There was no significant effect for type of job, \( (F = .60, \quad P < .66) \), indicating that there is no significant difference in knowledge scores between the different job types.

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Table 6 Mean Scores Obtained on Knowledge Questionnaire by Each Job Type

<table>
<thead>
<tr>
<th>Job Title</th>
<th>Mean Score</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care Staff</td>
<td>6.39</td>
<td>1.92</td>
</tr>
<tr>
<td>Night Staff</td>
<td>6.00</td>
<td>1.35</td>
</tr>
<tr>
<td>Team Leader</td>
<td>7.17</td>
<td>2.23</td>
</tr>
<tr>
<td>Education Officer</td>
<td>7.17</td>
<td>2.64</td>
</tr>
<tr>
<td>Manager</td>
<td>6.72</td>
<td>2.10</td>
</tr>
</tbody>
</table>

Figure 4 Mean Knowledge Scores for Each Job Type
Predictors of knowledge were then assessed through multiple regression controlling for the effects of job title, amount of training and length of experience (see table 7). None of the factors were shown to predict level of knowledge, \( F(3, 36) = 1.79, \text{ signif } F = 0.16 \).

It is noted, however, that training as a predictor approached significance, \( T = 1.96, \text{ Sig } T = .053 \). To investigate the relationship between training and knowledge a Pearson product moment correlation was conducted which showed a positive correlation between these two factors, \( t = .28 p < .018 \), indicating that number of training courses attended is linked to knowledge scores.

Table 7 Result of Multiple Regression for Knowledge

<table>
<thead>
<tr>
<th>Variable</th>
<th>Beta</th>
<th>T</th>
<th>Sig T</th>
</tr>
</thead>
<tbody>
<tr>
<td>Job title</td>
<td>-.036</td>
<td>-.25</td>
<td>.80</td>
</tr>
<tr>
<td>Training</td>
<td>.25</td>
<td>1.96</td>
<td>.053</td>
</tr>
<tr>
<td>Experience</td>
<td>.049</td>
<td>.32</td>
<td>.75</td>
</tr>
</tbody>
</table>
5.5 Involvement

Mean scores for importance of involvement and actual involvement are shown for each job type in table 8 and in figure 4.

**Table 8 Mean Scores for Ratings of Importance of and Actual Involvement**

<table>
<thead>
<tr>
<th>Job Title</th>
<th>Importance of Involvement Mean</th>
<th>Importance of Involvement SD</th>
<th>Actual Involvement Mean</th>
<th>Actual Involvement SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care Staff</td>
<td>8.43</td>
<td>1.6</td>
<td>4.82</td>
<td>2.15</td>
</tr>
<tr>
<td>Night Staff</td>
<td>6.75</td>
<td>3.96</td>
<td>3.33</td>
<td>2.77</td>
</tr>
<tr>
<td>Team Leader</td>
<td>7.5</td>
<td>1.87</td>
<td>6.5</td>
<td>1.64</td>
</tr>
<tr>
<td>Education Officer</td>
<td>8.67</td>
<td>1.63</td>
<td>6.17</td>
<td>2.32</td>
</tr>
<tr>
<td>Manager</td>
<td>9.36</td>
<td>3.96</td>
<td>8.18</td>
<td>1.72</td>
</tr>
</tbody>
</table>

**Figure 5 Mean Scores for Ratings of Importance of Involvement & Actual Involvement**

![Bar chart showing mean scores for importance of involvement and actual involvement for different job titles.](chart.png)
A one way analysis of variance was carried out between each group's mean score for importance of involvement in behavioural programming. This was significant, \( F(4,67) = 2.54 \ p< .047 \), indicating that there was a significant difference between scores for different job types. A Tukey's Honestly Significant Difference (HSD) test indicated that the difference was located between managers and all other job types. This suggests that managers rate that it is more important for them to be involved in behavioural programming than education officers, team leaders, care staff and night staff rate that it is for them to be.

A one way analysis of variance was also carried out on ratings of actual involvement in behavioural programming. This again was significant, \( F(4,67) = 8.29 \ p< .001 \), indicating that different job types are more involved than others in behavioural programming. A Tukey's Honestly Significant Difference (HSD) test was then carried out to look at where these differences in ratings were. This showed that night staff rate themselves as significantly less involved in behavioral programming than all other job types and that managers rate themselves as significantly more involved in behavioral programming than all other job types.

5.6 Factors Influencing Staffs' Ratings of Acceptability of Behavioural Interventions

To look at whether staff variables such as 1) type of job, 2) amount of experience of people with challenging behaviour, 3) number of training courses attended, 4) knowledge of behavioural principles, 5) ratings of importance of involvement in behavioral programming and 6) actual involvement in behavioral programming can predict staffs'
ratings of acceptability of behavioural interventions a stepwise multiple regression was carried out. The main findings from this are summarized in table 9.

Table 9. Results of Stepwise Multiple Regression for Predictors of Acceptability

<table>
<thead>
<tr>
<th>Variable</th>
<th>T Value</th>
<th>Sig T Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Job Title</td>
<td>-.17</td>
<td>.87</td>
</tr>
<tr>
<td>Training</td>
<td>-.12</td>
<td>.90</td>
</tr>
<tr>
<td>Knowledge</td>
<td>.62</td>
<td>.53</td>
</tr>
<tr>
<td>Experience</td>
<td>-.06</td>
<td>.95</td>
</tr>
<tr>
<td>Importance of involvement</td>
<td>-1.09</td>
<td>.27</td>
</tr>
<tr>
<td>Actual involvement</td>
<td>-2.49</td>
<td>.015</td>
</tr>
</tbody>
</table>

The only variable which was entered into the equation and to have a significant result was actual involvement, F(1,70) = 6.20 p< .015. To investigate this finding further a Pearson product moment correlation was conducted. This showed that there was a negative correlation between actual involvement and total acceptability score, r = -.29 p< .015. This suggests that the more involved a person is in behaviour programming the less acceptable they find behavioural interventions to be.
6.00 Discussion

The main findings of this research were:-

1) With one exception, time out, accelerative techniques (i.e. redirection, DRO and counselling) were rated as more acceptable than reductive techniques (i.e. medication and restraint).

2) Redirection and counselling were both rated as acceptable interventions.

3) Reductive techniques were rated as more acceptable when used with a severe challenging behaviour than with a mild challenging behaviour.

4) Redirection was rated as the most acceptable intervention for all challenging behaviours and restraint the least acceptable intervention.

5) Acceptability and effectiveness were positively correlated for both accelerative and reductive techniques.

6) No differences were found between scores on the knowledge questionnaire for different job types.

7) All job types rate that it is important for them to be involved in behavioural programming although in reality managers are more involved than other job types and night staff less involved.

8) Actual involvement is the only factor related to acceptability of behavioural interventions in that the more involved a person is in behavioural programming the less acceptable they find behavioural interventions to be.
6.1 Acceptability of Interventions

Overall, the findings of the present study support the findings of previous research into social acceptability of behavioural interventions. As in the Tarnowski et al studies (1989 & 1990) and the Miltenberger et al study (1989), it was found that with one exception, time out, accelerative techniques (i.e. redirection and counselling) were rated as more acceptable than reductive techniques (i.e. medication and restraint). Although time out is a reductive technique it was rated in this study as being more acceptable than DRO. This may reflect the philosophy of the care homes where the study was carried out in that time out is not viewed as a punitive intervention but as a means of keeping the individual and other residents safe from harm and providing a space for the individual to calm down, so avoiding an escalation in the behaviour. In this respect, time out can help the individual to learn other more appropriate behaviours and therefore is perhaps viewed by staff as an accelerative technique rather than a reductive technique. It may also reflect the nature of the challenging behaviours that staff are having to respond to. If staff have to frequently respond to behaviours which are likely to cause harm to the person or are likely to endanger others then an immediate, effective intervention such as time out is needed in the short term. This does not preclude the use of other techniques (e.g. counselling and redirection) in addition to this form of intervention as a longer term measure in helping both the staff and the individual to gain an insight into the precipitating and maintaining factors of the behaviour.

In terms of overall acceptability of interventions, as predicted both redirection and counselling are rated as acceptable techniques for use with challenging behaviour. In fact
Redirection is rated as the most acceptable intervention for responding to challenging behaviour. Redirection is probably the least restrictive of the behavioural techniques and for this reason it is often linked with a gentle teaching approach. This highlights the recent shift away from managing and responding to problem behaviours, (i.e. a reactive approach), and a subsequent move towards understanding and preventing the problem behaviours from taking place, (i.e. a proactive approach). It is likely that staff perceive redirection as being more respectful to the individual and less invasive than other behavioural techniques. Redirection places a great deal of emphasis on the use of techniques for understanding the antecedents and maintaining factors of a challenging behaviour i.e. functional analysis and the multi-component model. It is therefore important for all staff, at all levels, to have a good understanding of functional analysis so that they are able to notice the antecedents to a person's challenging behaviour and intervene early enough to prevent the behaviour from taking place. The extent of staff's understanding of functional analysis and the multi-component model was not investigated in this study. Further research needs to be directed at this question and if necessary this should be an area included in staff training.

It was predicted that counselling, being viewed as an accelerative intervention, would be rated as more acceptable than time out and medication. The results from this study indicate that it is not seen as being more acceptable than these interventions. One explanation for this is that as counselling is a relatively new and longer term treatment for challenging behaviour staff have not had the opportunity to experience the beneficial effects that counselling may have on their clients' behaviour. Staff may not actually know what could be achieved through counselling i.e. the individual becoming
more aware of their own challenging behaviour and using self help techniques to deal with difficult situations (as discussed in Williams and Jones, 1996). If this is the case then other treatment methods have to be used in addition to counselling which have an immediate effect on the challenging behaviour i.e. time out and to a lesser extent medication. That counselling has been rated as acceptable reflects the general trend in learning disabilities towards helping clients to understand their emotions and feelings and how these might effect their behaviour.

Surprisingly, DRO was not rated as being more acceptable than time out or medication in the present study. This is at odds with the findings of previous researchers e.g. Kazdin (1980), Witt & Robbins (1985), Miltenberger et al (1989) and Tarnowski et al (1989 &1990), who all found DRO to be rated as more acceptable than time out and medication. One previous study, Miltenberger et al (1990), had found similar results to those in the current study in that no differences were found between DRO and time out when used with young children. Such differences in findings may be due to the fact that all of these studies have been carried out on differing populations ranging from young children with tantrums to young adults with learning disabilities displaying severe self injurious behaviour. One reason for the current finding is that care staff may think that by differentially reinforcing other behaviours they are not in fact attending to and treating the problem behaviour. Furthermore, certain behaviours may appear too severe and unpredictable for DRO to be of any use. However, as will be discussed below DRO was rated as more acceptable for severe behaviours than mild behaviours so this would appear not to follow. DRO compared to other interventions is relatively time consuming and needs to continue even in the absence of the challenging behaviour. It may be this
time factor that is influencing staff's acceptability ratings of DRO. Support for this view comes from previous research which has shown less time consuming techniques to be rated as more acceptable than more time consuming techniques, e.g. Witt & Martens (1983), Elliott et al (1984) and Witt et al (1984).

Medication is seen as being more acceptable than restraint but not significantly less acceptable than counselling, time out or DRO. Again, this is a surprising finding and is not supported by previous research, although in a study carried out by Kazdin (1984), children aged 7 - 12 rated medication as the most acceptable form of treatment for an eight year old girl with aggressive and oppositional behaviour. It may be that medication is seen as being a useful addition to accelerative techniques which by themselves may take time to have an effect. In this way medication can provide a starting point for intervening so that behavioural techniques can then be implemented. It may also be the case that staff were not aware of the side effects that certain medications can have on the individual and in this study staff were not informed of the type of medication used. If details of possible side effects had been included along with the case descriptions then it is possible that medication would have been rated as less acceptable than it actually was. Kazdin (1981), found that information concerning the adverse side effects of certain interventions reduced the acceptability ratings for these interventions.

As predicted, restraint was viewed as the least acceptable intervention overall and therefore adds support to the findings of previous research. Even though restraint is viewed as the least acceptable intervention, staff rate its use as more acceptable for severe behaviours than mild behaviours. This perhaps indicates that for behaviours where
the individual may hurt themselves or others, staff realise that they have to intervene quickly and effectively to stop the behaviour. The effect of problem severity will be discussed in more detail below.

6.2 Effect of Severity Level

As in the Tarnowski et al (1989) and Miltenberger et al (1989) studies, the present study found that acceptability ratings for interventions varied depending on the severity of behaviour they were being used to treat. Restraint, medication and time out are all rated as being more acceptable for use with a severe behaviour such as self-injurious behaviour and physical aggression than for a mild behaviour e.g. verbal aggression and stereotypy. Even when dealing with severe behaviour problems staff still rate redirection as being the most acceptable form of intervention followed by time out. This indicates that staff are aware of the serious consequences of severe behaviour problems both for the person displaying the behaviour and for others and realise that a more immediate, effective intervention is called for in the short term. The fact that redirection continues to be rated as highly acceptable indicates that staff are aware that reductive techniques are effective short term interventions but that in terms of effecting a longer term change in behaviour other techniques are perhaps more effective. This would tend to suggest that staff see effective techniques as acceptable techniques. This was found to be the case in the current study as will now be discussed.
6.3 Effectiveness and Acceptability

As predicted staff view interventions which are seen to be effective as techniques which are acceptable. For accelerative techniques there was a strong correlation between these two factors, supporting the findings of Kazdin (1984) and Von Brock and Elliott (1987). It was thought that no such correlation would be found for reductive techniques in that staff may see that a reductive technique is effective for responding to a challenging behaviour but they may not necessarily see it as an acceptable technique to use. An example of this would be the use of restraint for a stereotypical behaviour. The technique would prevent the behaviour and would therefore be an effective technique to use but it would not be seen as acceptable for this sort of behavioural problem. However, in this study there was a positive correlation between acceptability and effectiveness for reductive techniques. This would tend to suggest that if staff view a reductive technique as being effective for a behavioural problem then they will also perceive this as an acceptable technique to use. However, that there was a stronger correlation between acceptability and effectiveness for accelerative techniques than for reductive techniques indicates that staff are perhaps making some distinction between the use of accelerative and reductive techniques. In this study no information was given to staff about the effectiveness of different interventions for different behavioural problems so that judgements had to be based upon their own experience of these techniques. Kazdin (1984), found that medication procedures described as more effective in the case descriptions were rated as more acceptable by respondents. It is possible that had information about the effectiveness of interventions been included in the current study then staff may have made more of a distinction between accelerative and reductive techniques in terms of acceptability and effectiveness of interventions.
6.4 Problem x Intervention Match

The findings of this study suggest that certain interventions are seen as being more acceptable/effective for different behavioural problems. For three of the behaviour problems: self-injurious behaviour, verbal aggression and stereotypy, redirection is rated as being the most acceptable/effective intervention by staff. Restraint is rated as the least acceptable/effective technique for all four behaviours. For physical aggression there is no significant difference between scores for redirection, medication and counselling. It is likely in this case that the physical aggression is directed towards staff and therefore they are directly affected by the behaviour as they are in danger of being hurt. This is unlike the other three behaviours where there is little or no likelihood of staff being hurt by the behaviour. Support for this view comes from Lowe and Felce (1995) who conclude in their study into severity of challenging behaviours that, “Such behaviours as aggression, temper tantrums, disruptiveness and non-compliance are likely to have a direct effect on carers. They clearly constitute a problem to them.” This would perhaps lead staff to the conclusion that redirection on its own is not enough to control this behaviour and the use of medication is also necessary to help the individual to remain calm. Staff may also see counselling as a way for the individual to gain some insight into their aggressive behaviour and to find ways of regulating their own behaviour.

The results suggest that severity of challenging behaviour is an important factor which staff take into account when deciding on the acceptability of interventions. For severe behaviour problems time out is rated as the second most acceptable intervention compared to counselling for mild problems. Again, for severe problems DRO is rated as the second least acceptable intervention compared to medication for mild problems. It
is likely that staff are being guided in their ratings of acceptability by their views on how effective interventions are for different behavioural problems. The relationship between acceptability and effectiveness is a complicated one and is an area that requires further study.

The finding that staff rate certain interventions as more acceptable for certain problems needs to be taken seriously by clinicians when devising behavioural programmes. It is likely that staff are going to feel more comfortable and confident carrying out a procedure which they view as an acceptable procedure. In this way, the inconsistency so often found in the implementation of behavioural programmes can be minimised. However, the finding that effectiveness and acceptability are positively correlated indicates that clinicians can alter staff’s perceptions of an intervention by giving them information about its effectiveness. Further research needs to be carried out within the field of learning disabilities to look at the effect of giving information concerning effectiveness of intervention on care staff’s ratings of acceptability of intervention. This is an area which also needs to be included in staff training.

6.5 Knowledge of Behavioural Principles

The findings on behavioural knowledge were not as predicted. In terms of mean scores for the knowledge questionnaire there was no significant difference between the scores for any of the five job types. It was predicted that managers would have a higher level of knowledge than other members of staff but this was not found to be the case. In general, the scores obtained are lower than expected. There are several possible reasons for this. First, the questionnaire was a shortened form of a much longer questionnaire.
It may be that the choice of items for the shortened questionnaire was not diverse enough to fully test staff's knowledge. Second, there is no standardized sample to compare these scores to. To investigate whether these findings are meaningful and indicate low levels of knowledge of behavioural principles amongst care staff, it would perhaps be wise to give the questionnaire to a larger sample of people including clinical psychologists to obtain a meaningful comparison group. It would also be of interest to repeat this part of the study using a different questionnaire such as the 44 item "Knowledge of Behavioural Methods Inventory" devised by McKeegan and Donat (1988). This would indicate whether the lower than expected scores are a result of the way the questionnaire was shortened or in fact represent a true indication of staff's knowledge of behavioural principles. Another possible reason for this pattern of results can be found by looking at the individual answers which staff gave to the questions. These tend to indicate that staff are interpreting clients' behaviour within a psychodynamic/client centred framework and are responding to questions from this perspective rather than a behavioural perspective. This can be seen by looking at the responses to question one of the questionnaire:

Desirable and undesirable behaviour are most alike in that they are:

a. The results of emotions and feelings.
b. Habits and therefore are difficult to change.
c. Ways a person uses to express themselves.
d. The result of learning.

The correct response to this question is d although the majority of respondents chose a or c. This reflects the growing integration of psychodynamic, cognitive and behavioural approaches for providing a wider range of possible interventions for responding to challenging behaviour.
If knowledge of behavioural principles is low amongst staff working with people with a challenging behaviour then it is important for this to be addressed through staff training so that all staff have a good understanding of the interventions they are being asked to carry out.

In terms of factors influencing staffs’ knowledge of behavioural principles, job title, training and experience proved to be non-significant. However, training was nearing significance and was the only factor to be positively correlated with knowledge. This suggests that staff who have attended relevant training courses have a better understanding of behavioural principles. This is a reassuring finding and indicates how important it is for all staff at all levels to receive appropriate training on behavioural principles. Previous research (i.e. Donat and McKeegan, 1990 & Donat et al, 1991) indicate a strong association between level of education and behavioural knowledge. The present study did not look at the educational level of staff and this may be an important factor to address in future research.

Results from the knowledge questionnaire need to be interpreted with caution as all the questionnaire is able to assess is an academic knowledge of behavioural principles. It is not able to tell us how staff use this knowledge to guide their practice or indeed whether there is a relationship between knowledge scores and ability to apply behavioural principles in real situations. To investigate this further, research needs to focus on the actual implementation of behavioural interventions within community homes.
6.6 Involvement

This is an area which has been largely neglected within the existing literature on behavioural programmes and as yet, there is nothing reported about staff involvement in the wider clinical psychology literature.

As predicted all levels of staff rate that it is important for them to be involved in the planning and implementation of behavioural programmes. However, managers rate that it is more important for them to be involved than it is for other staff members. This is not a surprising finding as it is generally accepted as being part of the manager’s job to liaise with the clinical psychologist, and reflects their experience and training. It is an interesting finding that all other staff members from education officers to night staff rate that it is important for them to be involved in behavioural programming. This possibly reflects the fact that it is these staff members who implement the programmes on a daily basis and who therefore have information and opinions about the effectiveness and suitability of the programmes they are being asked to implement. Another reason for this finding may be the introduction of key-worker/named nurse systems, where one staff member acts as a “key” person in an individual’s care. This means that they have a more detailed knowledge of this person than other staff members and therefore feel they have an important contribution to make to the planning and devising of behavioural programmes for their key client.

As predicted, ratings of actual involvement vary as a function of job type with managers rating themselves as being more involved than other staff groups and night staff rating themselves as less involved than other staff groups. For more senior members of staff
i.e. managers, team leaders and education officers there is very little difference between their ratings for importance of involvement and actual involvement. However, there appears to be more of a discrepancy between these two ratings for care staff and night staff. This means that in reality care staff and night staff are less involved in behavioural programming than they think they should be. Looking to the organisational literature for a model, (i.e. Campbell and Pritchard, 1976 and Mishra and Gupta, 1994), this is likely to lead to dissatisfaction amongst care staff and night staff which might manifest itself in terms of decreased levels of motivation and commitment to the behavioural programme leading to an inconsistent approach. As behavioural techniques rely on a consistent approach it is important that factors which may lead to inconsistencies are minimised. For this reason it will be necessary for managers and clinical psychologists to look at how all members of the staff team can be fully involved in the decision making process around behavioural programming. Models of service delivery are currently being developed with this in mind e.g. the consultancy model. As this is an area which has not previously been investigated there is a need for more research into this area to gain a fuller understanding of how staff’s thoughts and feelings about their involvement effect their implementation of behavioural programmes, and whether increased involvement does actually lead to increased levels of motivation and commitment.

6.7 Factors Influencing Staff’s Ratings of Acceptability of Behavioural Interventions
The findings from this part of the study were not as expected. It was found that ratings of acceptability were not related to type of job, amount of experience, number of training courses attended, knowledge of behavioural principles or ratings of importance of
involvement. Previous research has only looked at the relationship between job type and experience and acceptability ratings but with varying results. Witt and Robbins (1985), found that less experienced teachers rated behavioural procedures as more acceptable than experienced teachers. Tarnowski et al (1990), found that staff working in a behavioural treatment milieu rated behavioural techniques as more acceptable than staff working in a developmental treatment setting. Miltenberger et al (1989), found that institutional staff favoured restrictive behavioural procedures more than community staff but as in the present study found no differences between direct care staff or supervisory staff.

However, the present study did find a relationship between acceptability ratings and ratings of actual involvement in behavioural programming, (albeit only a mild correlation), in that the more involved a member of staff is in behavioural programming the less acceptable they rate behavioural interventions to be. This is a surprising finding although supports the findings of Witt and Robbins (1985), mentioned above. One possible reason for this is the fact that staff members who are more involved in behavioural programming will also be more aware of the limitations of this approach and will have had more experience of times when behavioural interventions have failed to bring about the desired changes in a person's behaviour. Following on from this it may also be the case that people have become disillusioned with the failure of behavioural interventions to bring about quick and lasting changes in behaviour and are therefore looking more towards alternative approaches to bring about the lasting, long term changes they want to see. This is an area which requires further investigation perhaps in the form of qualitative research to access care staff's thoughts and opinions about
behavioural interventions. It would be necessary to replicate this part of the study to see if this finding is consistent.

6.8 Limitations of the Present Study

To ensure that all staff had a thorough understanding of the interventions and the problem behaviours they were being used to treat, all of the case descriptions and interventions were based upon actual cases within the community homes. By doing this it was hoped that staff would use their experience of the problem behaviours and interventions to guide their responses. This addresses the questions raised over the ecological validity of analogue research by Reimers et al (1987) and Witt and Robbins (1985) who state that often respondents had no opportunity to observe the treatments they were being asked to rate, their effects on the problem behaviour or the outcome. Although the current study has attempted to increase the ecological validity found to be lacking in previous research it remains unclear if staff’s beliefs and attitudes have an effect on the way behavioural interventions are carried out on a day to day basis e.g. does the fact that an intervention is rated as less acceptable than another mean that staff will not carry it out as consistently? Future research will need to address this issue by looking directly at the way staff carry out behavioural interventions within the community homes and by linking this with their acceptability ratings for these interventions.

The present study was carried out within six privately run community homes owned by the same company. This raises some questions about the generalisability of the findings to other community settings. However, the community houses studied provide placements for people of differing ages and abilities and the staff are exposed to a wide
range of challenging behaviours. In this respect the houses can be seen as being a representative sample of community care homes. Unlike many care homes though, C.H.O.I.C.E employ full time assistant psychologists and a part time consultant psychologist so that all behavioural interventions and treatment plans are carefully monitored and reviewed. This may alter the perceptions of the staff towards behavioural interventions compared to staff in care homes where there is limited or no clinical psychology input as they are more aware of the importance of this type of intervention.

The present study aimed to investigate a number of issues relating to the acceptability and effectiveness of behavioural programmes and staff variables which may influence this. In this respect the study was very broad and it was not possible to investigate certain areas in depth. Areas such as the effectiveness of behavioural interventions and the relationship this has with acceptability and the role of staff involvement need to be expanded upon and looked at in more detail. The present study can be viewed as a useful introduction to these areas and as a way of introducing these factors into the debate on acceptability.

The shortening of existing questionnaires for use in this study needs some comment. Although it was necessary to shorten the questionnaires in order to minimise the time taken to complete them it may be that the validity and reliability of the shortened form is lower than the originals. Care was taken when shortening the questionnaires to choose the most representative items and the psychometric properties of the scales were used to aid this process. Replication of the study and further statistical analysis would be
needed to look at the validity and reliability of the shortened measures.

Despite the shortening of the measures the questionnaire was still lengthy and demanding of staff time. This may have caused a fatigue effect with staff not fully concentrating on all the case descriptions to the same degree. The order of presentation was not randomised to control for this and this is something which will need to be considered if the study were to be repeated.

6.9 Clinical Implications of the Findings

Several important clinical and service related implications can be drawn from the findings of the present study.

In order to increase the effectiveness of treatments for challenging behaviour, clinical psychologists should guide and be guided by staff's thoughts and opinions about different treatment interventions which can be seen by looking at their acceptability ratings for treatment interventions. As staff are clearly of the opinion that certain interventions are more acceptable for certain problem behaviours, psychologists should account for this when considering possible treatments for a challenging behaviour. In this way staff are likely to feel more comfortable implementing the intervention which in turn increases the consistency and effectiveness of the intervention. If the psychologist thinks it necessary to use an intervention which staff deem to be unacceptable s/he should spend
time with care staff explaining his/her reasons for this choice of intervention and answering their questions. As acceptability and effectiveness are positively correlated for all interventions it may be that by discussing the effectiveness of an intervention with staff they will change their view on the acceptability of the intervention.

Services need to look at their existing staff training programmes to ensure that staff are being taught the fundamental principles of behavioural interventions. The finding that training and knowledge scores are correlated indicates that staff do benefit and make use of training courses. As knowledge scores were lower than expected for all staff groups services should consider running programmes such as the one devised by Donat et al (1991), “Training Inpatient Psychiatric Staff in the use of Behavioral Methods: A Program to Enhance Utilization” for all staff from managers through to night staff. Training also needs to include information about the effectiveness of different interventions for treating challenging behaviour as the more effective staff perceive an intervention to be the more acceptable they are likely to find it. This will help to minimise the inconsistency so often found in the implementation of behavioural programmes.

Services need to address the issue of staff involvement in behavioural programming and to think about how they can increase this. The findings show that care staff and night staff are not as involved in the decision making process as they think they should be. As these are the people most likely to be implementing the behavioural programmes it is important that they feel they are being listened to in order to increase both motivation and commitment as discussed in the organizational psychology literature. Models of
service delivery such as the consultancy model where a psychologist consults with the entire staff team could be used to guide practice. Meetings about behavioural programming or other aspects of an individual’s care could also be opened up for all staff involved in that person’s care to attend. The timing of meetings should also be considered so that night staff have the opportunity to attend and have their views heard.

7.0 Conclusion

The present study has added support to the findings that accelerative techniques are rated as more acceptable than reductive techniques although ratings vary as a function of severity of behaviour. Two interventions, redirection and counselling, not previously researched have been found to be acceptable and effective techniques for treating challenging behaviour. As in previous research, effectiveness and acceptability have been shown to be related. Findings on staff’s level of knowledge of behavioural principles indicates the need to improve staff training and the issue of staff involvement in behavioural programming needs to be addressed by services.

With the majority of long stay hospitals now closed the duty of care for people with challenging behaviour rests with community services. Community services have a duty to provide quality care for the people they serve. As stated by Emerson et al (1987), failure to do so has far reaching consequences not only for the people themselves but also for the future of community based services. One way of ensuring quality care is to look at care staff’s attitudes and beliefs about the work they are doing and how these influence their clinical duties. For this reason alone it is important to continue research within this area.
References


THE BRITISH PSYCHOLOGICAL SOCIETY (Division of Clinical Psychology). Purchasing clinical psychology services: Services for people with learning disabilities and their carers. Briefing paper No. 3.


Appendix 1

Letter giving Ethical Approval
TO WHOM IT MAY CONCERN

Dear Sirs,

Re: Research Study Conducted by Christopher Bennett
UCL Clinical Psychology Training Course

The proposal to conduct a research study by Christopher Bennett into the acceptability and effectiveness of methods of intervention using C.H.O.I.C.E. Ltd residential staff as subjects for the study has been read and discussed by the Company Ethics Committee.

Ethical approval has been granted to Christopher Bennett to conduct the research strictly as detailed in the research proposals. The only condition imposed is that any alterations or amendments to the proposal should be forwarded to the Ethics Committee for further discussion.

Yours sincerely,

Paul Gold
Managing Director
Chair of C.H.O.I.C.E. Ltd Ethics Committee
Appendix 2

Behavioural Knowledge Questionnaire
Code number:-

a. How long have you worked with people who display challenging behaviours?

b. On a scale of 1 - 10, (with 1 meaning not at all involved and 10 meaning totally involved), how involved are you in the planning and running of behavioural procedures in your home?

c. On a scale of 1 - 10, (with 1 meaning not at all important, and 10 meaning extremely important), how important do you think it is that you are involved in the planning and running of behavioural procedures in your home?

Please read the questions overleaf and each of its four possible answers. Sometimes more than one answer could be correct under certain circumstances, however, you should select the best answer or the answer that is most generally true. Place a tick beside that answer.
1. Desirable & undesirable behaviour are most alike in that they are:-
   a. The result of emotions and feelings.
   b. Habits and therefore difficult to change.
   c. Ways a person uses to express themselves
   d. The result of learning.

2. Probably the most important idea to keep in mind when first changing behaviour is:-
   a. To use both reward and punishment.
   b. To reward every time the desired behaviour occurs.
   c. To be flexible about whether or not you reward.
   d. To be sure the person understands why you want the behaviour to change.

3. When should a person who is just learning to dress himself be praised for the first time?
   a. When he gets his foot through the first hole in his underwear.
   b. When he gets his underwear completely on.
   c. When he asks to do it himself.
   d. When he has completely finished dressing himself.

4. Three of the following responses refer to forms of punishment which are mild and effective. Which one is not?
   a. Ignoring the undesirable behaviour.
   b. Sending someone to a dull room for a few minutes.
   c. Taking away something the person likes, (eg a dessert after supper).
   d. Shouting at the person.

5. Which of the following is the most effective form of punishment in the long run for reducing a person’s undesirable behaviour?
   a. Scolding her every time she does it.
   b. Occasionally shouting at her when she does it.
   c. Sending her to her room for five minutes every time she does it.
   d. Sending her to her room all afternoon every time she does it.

6. If a person gradually receives rewards less and less often for a behaviour, what is most likely to happen?
   a. He will soon stop the behaviour.
   b. He will be more likely to behave in that way for a long time.
   c. He will not trust the person giving the rewards.
   d. None of the above.

7. To record, graph and note the direction of the change of the behaviour is:-
   a. A minor, optional step in a behaviour change programme.
   b. An important step in a behaviour change programme.
   c. A procedure only employed by psychologists for research purposes.
   d. Time consuming and complicated. Therefore these procedures should only be used in special cases.
8. A major problem has been getting John to bed in the evening. Care staff have decided to change this and want to measure the relevant behaviours. Which is the best way for them to do this?

a. Each evening, record whether or not he goes to bed on time.
b. Chart his behaviour all day long, up to and including bedtime to try to find out what causes his not wanting to go to bed.
c. Each week, make a note of how easy or difficult it has been to get him to bed.
d. Ask John to keep his own record each week of how easy or difficult it has been to go to bed.

9. The first step in changing a problem behaviour is to:

a. Reward the person when they are behaving nicely.
b. Punish the person for misbehaviour.
c. Carefully observe the behaviour.
d. Seek help from a psychologist.

10. In changing a behaviour it is most important to use:

a. Methods which have been tested by others.
b. Consequences which are rewarding to the person.
c. Consequences which are punitive to the person.
d. Rewards which do not bribe the person.

11. Jane is doing a number of things that greatly disturb her carers. It would be best for them to:

a. Try to quickly eliminate all of these undesirable behaviours at once.
b. Select just a few behaviours to deal with at first.
c. Select the single behaviour they find most disruptive and concentrate on changing that.
d. Wait for about a month before beginning to try to change her behaviour to make certain that they are stable and persistent.

12. If you want to make a behaviour a long lasting habit, you should:

a. Reward it every time.
b. First reward it every time and then reward it occasionally.
c. Promise something that the person wants very much.
d. Give several reasons why it is important and remind the person of the reasons often.

13. Which of the following is probably most important in helping a person behave in desirable ways?

a. To teach him the importance of self discipline.
b. To help him understand right and wrong.
c. Providing consistent consequences for his behaviour.
d. Understanding his moods and feelings as a unique person.

14. How often a behaviour occurs is probably mostly controlled by:

a. The person’s attitude about her behaviour.
b. What happens to her at same time the behaviour occurs.
c. What happens to her just before the behaviour occurs.
d. What happens to her just after the behaviour occurs.
Appendix 3

Case Descriptions and Interventions
Overleaf are descriptions of four different types of challenging behaviour followed by six possible interventions for each of the behaviours described.

Please read each of the descriptions and the interventions and then answer the three questions which follow each intervention by making a mark at the appropriate point on the line, eg:-

* I would be willing to use this intervention with the residents in my home with similar problems.

* This intervention would be effective in this situation and in other situations.

* This intervention would quickly have an effect on the client's behaviour.

There are no right or wrong answers to the questions and different people may have different opinions. What we are interested in are your views.

Please answer all the questions following each intervention, do not leave any out.
Angus is a 25 year old man with a severe learning disability who is resident in a community house. At times Angus will become verbally abusive to people around him. This will take the form of swearing at them, threatening them eg: “I’m going to beat you up”, and occasionally spitting at them. He has never been physically abusive towards anybody.
Interventions

a. If Angus is not verbally abusive for a specified period of time he is given a small reward such as listening to a song that he likes and is praised by staff. If he is verbally abusive during this time the reward is put off for a period of time.

* I would be willing to use this intervention with the residents in my home with similar problems.

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b. Once a week Angus meets with a counsellor who helps him to think about the reasons for his behaviour.

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When Angus is verbally abusive he is immediately taken to a safe room where he is told he will need to stay until he has calmed down. Staff stand outside of the room not interacting with him. Every two minutes staff check to see if he has calmed down. Once calm Angus is allowed to return to his usual activities.

* I would be willing to use this intervention with the residents in my home with similar problems.

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d. Twice a day Angus is given medication to help him to remain calm.

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e. Every time Angus is verbally abusive towards others he is immediately taken to a chair where he is restrained by staff. Nothing is said to him whilst he is being restrained. Once he has calmed down he is allowed to get up and return to his usual activities.

* I would be willing to use this intervention with the residents in my home with similar problems.

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g. When it appears that Angus is about to become verbally abusive staff try and engage him in an activity he likes. He is praised for his participation in this activity.

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PTO.
Clare is a 20 year old woman with a severe learning disability who is resident in a community house. At times Clare will attack staff members and other residents in the house. This will take the form of hair-pulling, biting people on the face and grabbing hold of people by the throat.
**Interventions**

a. At times when it looks as if Clare is going to attack staff or other residents, staff will attempt to engage her in another activity which she enjoys. She should be praised for her participation in this activity.

* I would be willing to use this intervention with the residents in my home with similar problems.

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b. At a set time each day, staff administer medication to Clare which helps her to remain calm

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c. Every time Clare attacks someone she is escorted by staff to a safe environment where she is told she will have to remain until she has calmed down. Staff will stay with her but will remain neutral in their interactions with her. Every two minutes staff will check to see if Clare has calmed down. Once she is calm she is allowed to return to her usual activities.

* I would be willing to use this intervention with the residents in my home with similar problems.

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d. Once a week Clare meets with a counsellor to explore the reasons for her behaviour.

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e. If Clare does not attack anybody within a specified time period, (eg. 10 minutes), she is given a small reward such as a cup of tea and is praised by staff. If she does attack someone during this time period the reward is put off for a short period of time.

* I would be willing to use this intervention with the residents in my home with similar problems.

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f. Every time Clare attacks someone she is immediately taken to a chair where she is restrained. Nothing is said to her whilst she is being restrained. After a short amount of time she is allowed to get up and return to her usual activities.

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PTO.
Paul is a 21 year old man with a severe learning disability who is resident in a community house. At times Paul will bang his fists against his head or will hit his head very hard against the floor. He will continue doing this until his ears bleed. He has lost the hearing in one ear and is partially deaf in the other due to this behaviour.
Interventions

a. Each time staff observe Paul banging his head, they will immediately place him on the floor and use restraint so that he cannot get up. Nothing is said to him whilst he is being restrained. After a short amount of time Paul is released and allowed to return to his usual activities.

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b. If Paul does not bang his head for a specified amount of time, (eg: 10 minutes), he is immediately given a small reward such as a biscuit and is praised by staff. If he does engage in the behaviour during the specified time period, the reward is put off for a short period of time.

* I would be willing to use this intervention with the residents in my home with similar problems.

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c. Each time Paul bangs his head staff will escort him to a safe environment away from activities/people where he is told he will need to stay until he has calmed down. Staff will stay with him, but remain neutral in their interactions with him. Staff will check every two minutes to see if Paul has calmed down. When he has calmed down he is allowed to return to his usual activities.

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d. When Paul appears as if he is about to bang his head staff should attempt to engage him in another activity which he enjoys. He should be praised for his participation in this activity.

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* This intervention would quickly have an effect on the client’s behaviour.

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<tbody>
<tr>
<td>Disagree</td>
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f. Once a week Paul will meet with a counsellor who will help him to explore the reasons for his behaviour.

* I would be willing to use this intervention with the residents in my home with similar problems.

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PTO.
Mary is a 23 year old woman with a severe learning disability who is resident in a community home. Mary will spend a great deal of time in the bathroom flushing the toilet. She will often pretend that she needs to use the toilet so that she can go to the bathroom to flush the toilet.
Interventions

a. Once a week Mary meets with a counsellor who helps her to explore the reasons for her behaviour.

* I would be willing to use this intervention with the residents in my home with similar problems.

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<tr>
<td>Disagree</td>
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<td>Agree</td>
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</table>

b. When staff suspect that Mary is about to go and flush the toilet they should attempt to engage her in another activity which she enjoys. She should be praised for her participation in this activity.

* I would be willing to use this intervention with the residents in my home with similar problems.

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<tr>
<td>Disagree</td>
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<td>Agree</td>
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</table>
c. Every time Mary flushes the toilet she is taken to a safe environment where she is told she will need to stay for a short period of time. The staff member will stay with her but remains neutral in their interactions with her. The staff member will check with her every two minutes or so whether she feels able to return to her usual activities.

| * | I would be willing to use this intervention with the residents in my home with similar problems. |
|---|---|---|
| Strongly | Not sure | Strongly |
| Disagree | either way | Agree |

| * | This intervention would be effective in this situation and in other situations. |
|---|---|---|
| Strongly | Not sure | Strongly |
| Disagree | either way | Agree |

| * | This intervention would quickly have an effect on the client’s behaviour. |
|---|---|---|
| Strongly | Not sure | Strongly |
| Disagree | either way | Agree |

d. Every morning staff administer medication which helps Mary to remain calm throughout the day.

| * | I would be willing to use this intervention with the residents in my home with similar problems. |
|---|---|---|
| Strongly | Not sure | Strongly |
| Disagree | either way | Agree |

| * | This intervention would be effective in this situation and in other situations. |
|---|---|---|
| Strongly | Not sure | Strongly |
| Disagree | either way | Agree |

| * | This intervention would quickly have an effect on the client’s behaviour. |
|---|---|---|
| Strongly | Not sure | Strongly |
| Disagree | either way | Agree |
c. If Mary does not flush the toilet within a certain time period she is given a small reward such as a biscuit and is praised by staff. If she does flush the toilet during this time the reward is put off for a short period of time.

* I would be willing to use this intervention with the residents in my home with similar problems.

| Strongly | Not sure | Strongly |
| Disagree | either way | Agree |

* This intervention would be effective in this situation and in other situations.

| Strongly | Not sure | Strongly |
| Disagree | either way | Agree |

* This intervention would quickly have an effect on the client’s behaviour.

| Strongly | Not sure | Strongly |
| Disagree | either way | Agree |

f. When staff observe Mary flushing the toilet she is restrained so that she cannot flush it. Whilst she is being restrained staff do not talk to her. After two minutes Mary is allowed to get up and return to her usual activities.

* I would be willing to use this intervention with the residents in my home with similar problems.

| Strongly | Not sure | Strongly |
| Disagree | either way | Agree |

* This intervention would be effective in this situation and in other situations.

| Strongly | Not sure | Strongly |
| Disagree | either way | Agree |

* This intervention would quickly have an effect on the client’s behaviour.

| Strongly | Not sure | Strongly |
| Disagree | either way | Agree |

Thank you for your time and effort in completing this questionnaire.
Appendix 4

Mean Acceptability Scores for Interventions for all

Four Challenging Behaviours
### Mean Acceptability Scores for the four Behavioural Problems from Least acceptable to Most Acceptable

#### Self Injurious Behaviour

<table>
<thead>
<tr>
<th>Behaviour</th>
<th>Restraint</th>
<th>DRO</th>
<th>Counselling</th>
<th>Medication</th>
<th>Time Out</th>
<th>Redirection</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>-1.26</td>
<td>1.04</td>
<td>2.20</td>
<td>2.59</td>
<td>2.81</td>
<td>4.40</td>
</tr>
</tbody>
</table>

#### Physical Aggression

<table>
<thead>
<tr>
<th>Behaviour</th>
<th>Restraint</th>
<th>DRO</th>
<th>Counselling</th>
<th>Medication</th>
<th>Time Out</th>
<th>Redirection</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>-.28</td>
<td>2.24</td>
<td>2.74</td>
<td>2.79</td>
<td>4.72</td>
<td>5.05</td>
</tr>
</tbody>
</table>

#### Verbal Aggression

<table>
<thead>
<tr>
<th>Behaviour</th>
<th>Restraint</th>
<th>Medication</th>
<th>DRO</th>
<th>Time Out</th>
<th>Counselling</th>
<th>Redirection</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>-4.06</td>
<td>.86</td>
<td>1.03</td>
<td>1.77</td>
<td>1.88</td>
<td>4.38</td>
</tr>
</tbody>
</table>

#### Stereotypical

<table>
<thead>
<tr>
<th>Behaviour</th>
<th>Restraint</th>
<th>Medication</th>
<th>Time Out</th>
<th>DRO</th>
<th>Counselling</th>
<th>Redirection</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>-5.14</td>
<td>-2.23</td>
<td>-1.80</td>
<td>.60</td>
<td>1.45</td>
<td>3.23</td>
</tr>
</tbody>
</table>
1.0. PROFESSIONAL DOSSIER

‘Evaluation of a Ten-Week Sexuality and Relationship Group for Men with Learning Disabilities’

It is now generally acknowledged that people with a learning disability, like anybody else, have sexual needs. Craft (1987), goes further stating that people with a learning disability have “rights” relating to their sexuality e.g. the right to be treated with respect and dignity, the right to have access to information about their bodies and those of other people and the right to be sexual and to form relationships with others. For professionals working with people with a learning disability there is a need to empower people to be able to express their sexuality in a safe and positive way. Often because of their intellectual disability people are not given access to information which allows them to learn about and discuss issues of sexuality and relationships. This can then lead to people with an intellectual disability either engaging in unsafe sexual practices or becoming the victims of abuse.

The sexuality and relationship group for men with a learning disability was established as a way to both educate men about sexuality and to provide a space to discuss relationship issues. The members of the group were assessed prior to and
three months after the group on their knowledge of sexuality and relationships. The results will be analysed to see if there is a significant increase in knowledge following participation in the ten-week group. The issues of devising and evaluating a group sensitive to the men’s needs will be discussed, as will the limitations of the group.

2.0. ACADEMIC DOSSIER

2.1. Critical Review One

‘Difficulties in the Diagnosis of Alzheimer’s disease in People with Down’s Syndrome’

The links between Down’s Syndrome and Dementia of the Alzheimer Type (DAT) have long been known. Nearly all of those with Down’s Syndrome over the age of 40 have the neuropathological markers for DAT and 36 per cent of those over the age of 35 show clinical signs of dementia (Lai & Williams, 1989). The issue of diagnosis of DAT in people with Down’s Syndrome is fraught with difficulty. As people with Down’s Syndrome also have an intellectual disability it is not appropriate to use assessment instruments to measure pre-morbid abilities and rate of cognitive decline which have been standardized on a non-intellectually disabled population. The results obtained may be a measure of the person’s intellectual disability rather than evidence of a dementing process. People with an intellectual disability are also more likely to show floor effects on these assessments meaning that useful comparison of scores over time cannot be made. Within the last few years a number of assessment tools have been adapted or devised to specifically aid the diagnosis of DAT in people with Down’s Syndrome. This review will evaluate the effectiveness of these measures.

Another important factor to take into consideration is that of differential diagnoses. Other medical and psychological conditions such as depression and hyperthyroidism can often mimic the symptoms of dementia giving rise to the phenomenon of ‘pseudo-dementia’. For people with intellectual disability and communication difficulties it may not be possible for them to vocalize their difficulties which means
that presenting symptoms can often be misdiagnosed. The literature on differential diagnoses will also be reviewed. Also the role of neuro-imaging techniques in the diagnosis of dementia will be discussed.

2.2. Critical Review Two

'What Evidence is there to Suggest that Psychoanalytic Psychotherapy is an Effective Form of Treatment for People with Learning Disabilities?'

In recent times there has been increasing interest in the application of psychodynamic/psychoanalytic thinking to the psychological difficulties of people with an intellectual disability. Indeed specialist psychodynamic/psychoanalytic centres such as the Tavistock Clinic in London provide a psychodynamic service specifically for people with an intellectual disability. The Government, in its document 'Signposts for Success in Commissioning and Providing Health Services for People with Learning Disabilities' (1998), states that treatment choice should be based on knowledge of the available information on effectiveness. For more traditional treatment approaches such as behavioural interventions, and to a lesser extent, cognitive behavioural approaches there is a considerable literature giving clear evidence of the effectiveness of these approaches for people with an intellectual disability. However, the literature on outcome for psychoanalytic psychotherapy with people with intellectual disability is small with only a handful of articles addressing this specific issue. Instead, effectiveness of this approach has been judged mostly from case reports. This review will look at whether case reports provide adequate evidence of positive outcomes for psychoanalytic psychotherapy for people with intellectual disabilities.

3.0. RESEARCH DOSSIER

3.1. Title of Proposed Research

'The Impact of Gay Identity Formation on the Mental Health of Men With Intellectual Disabilities: A Double Discrimination?'
3.2. Research Supervisor

Dr. Adrian Coyle

3.3. Background and Relevance of Research

Very little is known about the experiences of gay men with intellectual disabilities. Most of the literature on sexuality issues for people with intellectual disability focuses on areas such as safer sex, HIV prevention or sexual abuse (see McCarthy & Thompson, 1994; Murray & MacDonald, 1995). This leads to people with learning disabilities being viewed as either victims or perpetrators of sexual abuse rather than people with legitimate sexual needs. Although researchers such as Craft have drawn attention to the sexual needs and experiences of people with intellectual disabilities, this has been almost entirely from a heterosexual perspective. Same sex relationships for people with an intellectual disability have remained a taboo subject which few services have been willing to address. This can lead to same sex relationships being seen as "unvalued relationships" (CONSENT - an organisation providing therapy and counselling on sexuality issues to people with intellectual disabilities). If gay men with intellectual disabilities are exposed to, and internalise such discriminatory beliefs, this could have an effect on self-esteem which could then lead to self-devaluation, (Breakwell, 1986).

For men without intellectual disability it has been shown that the process of gay identity formation can have a serious impact on self-esteem and psychological well-being, (Grossman & Kerner, 1998; Meyer, 1995; Rothblum, 1994). As gay men with an intellectual disability have membership of more than one devalued group it could be argued that the effects on their self-esteem and psychological well-being would be even greater, (Davidson-Paine & Corbett, 1995). Other researchers argue that being gay per se, does not predict low self-esteem or high psychological distress. Frable, Wortman & Joseph (1997) posit that certain factors act as mediating variables i.e. community networks, personal visibility, cultural stigma and positive identity. Plummer (1975) cites the importance of contact with other gay men and "mentor
relationships" as important factors in determining psychological adjustment. For men with an intellectual disability the issue of awareness of stigma and anti-gay prejudice is an important factor. Breakwell (1986) states that something can only become a threat to identity when the individual becomes aware of it and its implications.

Services for people with intellectual disabilities operate within a framework of 'normalisation' (Wolfensberger, 1972) or 'ordinary living' (King’s Fund, 1980). This states that people with intellectual disabilities should be afforded the right to an ordinary life in the community, participating in and using community facilities. They should also have the right to choose which type of lifestyle they would like to adopt even if this is contrary to the mainstream, for example by being gay. As the process of gay identity formation can have serious consequences for psychological well-being it is important that more is known about this process for men with an intellectual disability.

This study will draw upon two frameworks:

1. Breakwell’s (1986) model of how people cope with threatened identities and the impact these experiences have on the individual, and

2. Frable et al’s.(1997) model of the interrelations between cultural stigma, personal visibility, community networks, positive identity and positive self perceptions.

Both of these frameworks can be used to understand how gay men with an intellectual disability cope with the experiences of being both gay and intellectually impaired, and the type of factors which may operate to protect their psychological well being.

3.4. Research Aims

1. To gain an understanding of gay identity formation for men with a learning disability.
2. To explore the effects of being gay on the emotional/psychological well-being of men with a learning disability.

3. To develop an understanding of the protective factors for emotional/psychological well-being for gay men with a learning disability.

3.5. Design and Methodology

As the intention of this study is to explore individual's experiences in depth it will be qualitative in nature. A semi-structured interview will be devised and participants will be interviewed by the author. All interviews will be audio-taped and transcribed. Measures such as the 'Rosenberg Self Esteem Scale' and the 'General Health Questionnaire' will also be administered to give a measure of both self-esteem and psychological distress. Both of these measures have been standardised on the general population and have norms available for comparisons.

It is anticipated that a minimum of ten men will be interviewed. Men will be recruited from community teams for people with an intellectual disability and organisations such as 'People First' (a self-advocacy group for people with intellectual disabilities). Men will be recruited from the London area and participation will be entirely voluntary. Ethical approval will be sought from the University of Surrey's ethics committee and the ethics committee of the NHS Trusts in which the author works. It is not anticipated that participation in the study will cause distress but the author is a chartered clinical psychologist and will be able to provide either a follow up debriefing session or referral to an appropriate agency if necessary.

The data will be analysed using interpretive phenomenological analysis (IPA). This approach emphasises engagement with individual participants' thoughts and behaviour. In this respect it adopts an 'insider' perspective on the research topic, being concerned with individuals' personal accounts or perceptions rather than producing objective statements. As IPA is interested in the meanings that individuals attach to events the analysis of the data needs to be interpretative in nature. IPA
therefore recognises that this process is influenced by and dependent on the interpretative framework of the researcher.

4.0. REFERENCES


PROFESSIONAL DOSSIER
CURRICULUM VITAE

CHRISTOPHER BENNETT
Chartered Clinical Psychologist

Summary of qualifications

• 1989 –1991 University of Sussex, B.Sc. (Hons) Experimental Psychology

• 1992 – 1993 Thames Valley University, Post Graduate Certificate in Applied Research Methods


Professional memberships

• Associate Fellow of the British Psychological Society

• Member of the British Psychological Society Division of Clinical Psychology

• Member of the British Psychological Society Lesbian and Gay Psychology Section

Employment history

• Current employment: Tertiary Assessment & Treatment Service, Hertfordshire Partnership NHS Trust.

  This is a service for people with learning disabilities who also have a psychiatric illness and/or challenging behaviour. I provide psychological assessment and treatment to service users and their families.

I worked in a low secure rehabilitation unit providing assessment and treatment to mentally disordered offenders detained under a section of The Mental Health Act.


I worked as part of a community team providing assessment and treatment for people with learning disabilities and their carers/families.

**Continuing Professional Development**

**Conferences & Training Events Attended Since Qualifying**

- Mental Health Issues for People with Learning Disabilities. BILD (one-day conference).


- Innovations in Autism, Dyslexia & Learning Disabilities. 5th World Congress Secretariat (one-day conference).

- The Supervisory Process & its Complexities. The Tavistock Clinic (one-day conference).

- Interpretative Phenomenological Analysis. University of Sheffield (one-day conference).

- Introduction to Systemic Therapy. Chelsea & Westminster Hospital (20 week in house training course).

- Recognising & Assessing Men’s Sexually Abusive Behaviour. CONSENT (two-day training course).

- Introduction to Cognitive Analytic Therapy. Homerton Hospital (one-day in house training course).

16
• Introduction to CBT for Psychosis. Homerton Hospital (two-day in house training course).

• Workshop for New Supervisors. University College London (one-day workshop).

• Introduction to Qualitative Methodology. University of Surrey (half-day workshop).

Conference & Workshop Presentations Given Since Qualifying


• Tizard Centre & CONSENT Saturday Seminars. Paper presented on running a support group for gay men with learning disabilities.


• Pavilion Conference: ‘Working with Diversity’. Workshop facilitated on working with gay men with learning disabilities
The Development and Evaluation of a Ten Week Sexuality & Relationship Group for Men with Learning Disabilities
1.0. Introduction

This clinical dossier will take as its focus a ten-week sexuality and relationship group undertaken by five men with a learning disability. The group was set up at the request of a housing provider for people with learning disabilities. Although sex education courses were available for women with a learning disability there was no local provision for sex education courses for men. The need for a sexuality and relationship course aimed particularly at men with learning disabilities was highlighted following the expression of sexually inappropriate behaviour from some of the male residents living in the community houses. This was thought by care staff to be linked to a lack of knowledge about appropriate and safe ways of expressing sexuality.

All of the men referred were assessed prior to the group commencing to ascertain their level of knowledge about sexuality and relationships. This information was used to help develop the agenda for the group and to provide a baseline measure of knowledge. Three months after the group had terminated the men were re-assessed to look for changes in their level of knowledge and to find out if information provided in the group had been retained over time.

Although it has long been recognised that sex education for people with learning disabilities is of paramount importance (Craft, 1994) it often remains a taboo subject for services, and can take second place to other areas of skills teaching viewed as being necessary for a safe and “normal” life within the community. Carson (1992) suggests that by adopting such a position services are failing in their duty of care towards people with learning disabilities.

However, even when sex education courses have been offered it is unclear how effective these have been as few programmes have been adequately evaluated (Whitehouse & McCabe, 1997). This is apparent from looking at the available literature on sex education programmes for people with learning disabilities where emphasis has mostly been placed on the development of programmes rather than outcome. When outcome has been discussed in the literature, this has usually been in relation to measuring increases in sexual knowledge.
However, even when outcome measures show that participants’ knowledge has increased following attendance at a sex education programme, there remains the issue of how, if at all, people with learning disabilities use the knowledge they have acquired, how this changes their perception of themselves as sexual beings and what impact this has on their behaviour.

Before the sexuality and relationship group carried out by the author is discussed in more detail, the literature on sex education, and in particular on the evaluation of sex education programmes, will be reviewed as this was used to inform the development of the current group.

1.1. Literature Review

1.1.1. A Rationale for Sex Education

Following the closure of long stay hospitals and the resettlement of individuals back into local communities, services adopted a model of normalisation (Nirje, 1976) to guide their service delivery. This states that people with learning disabilities should live ordinary lives in the community with the same rights and opportunities as any other member of society. Inherent in such a model is the right of people with learning disabilities to express themselves sexually. However, it has been argued by some that to be able to express their sexuality in a safe and socially appropriate way, people with learning disabilities need to have access to sex education programmes (see Craft & Craft, 1983; Foxx, McMorrow, Storey & Rogers, 1984).

This recognition of the sexual rights of people with learning disabilities and the need for appropriate sex education is by no means a recent phenomenon. In 1971 the ‘United Nations Declaration of the Rights of the Mentally Retarded’ stated that individuals with mental retardation (i.e. learning disabilities), had the right to:
1. Receive training in social/sexual behaviour that will open more doors for social contact with people in the community.
2. All the knowledge about sexuality that they can comprehend.
3. Enjoy love and be loved by the opposite sex, including sexual fulfilment.
4. Express sexual impulses in the same forms that are socially acceptable to others.
5. Birth control services which are specialised to meet their needs.
6. Marry
7. Have a voice in whether or not they should have children.
8. Supportive services.

Several years later the Warnock Committee on Special Educational Needs (DES, 1978) noted that:

"At present sex education and counselling on sexual relationships tend to be badly handled generally. This is unfortunate for all young people, but is particularly serious in the case of young people with severe disabilities, whose opportunities for personal development through self-education are so limited compared with those of other young people, and for whom the problems of adolescence are likely to be increased by their disability....Advice on sexual relationships should be both realistic and humane and should always be planned within the concept of education in personal, social and moral responsibility".

It is therefore widely accepted, and has been for sometime, that people with learning disabilities have a right to well-planned and high quality sex education. As stated above one of the main reasons for this is to empower people with learning disabilities to have the same sexual opportunities as other people in society. In order to have the same sexual opportunities as others, and to be able to express themselves sexually in a safe way, people with learning disabilities need to have information on a range of topics including: sexually transmitted diseases and their prevention, prevention of pregnancy and an understanding of socially appropriate sexual behaviour (Craft & Craft, 1983). This is highlighted in a study carried out by McCabe & Cummins (1996) who compared the sexual knowledge and experience of college students with that of people with learning disabilities. They found that people with learning disabilities had more experience of pregnancy and sexually transmitted diseases than did a student population.
It has been argued (see Baladerian, 1991; McCabe, Cummins & Reid, 1994; Sobsey & Doe, 1991) that another vital role of sex education is in helping to prevent sexual abuse. Without appropriate sex education it is difficult for people with learning disabilities to know what is and is not sexually appropriate behaviour. Taken together with a lack of assertiveness and poor communication skills, a lack of knowledge about sexual abuse can make people with learning disabilities more vulnerable to abuse than others. In a study carried out by Sobsey (1994), 31.7 per cent of the carers of people with learning disabilities who had been abused, identified a lack of knowledge about sexual assault as one of the causative factors in the abuse. McCabe, Cummins and Reid (1994), in a comparative study of college students with people with learning disabilities, found that the level of sexual abuse experienced by both groups was similar. However, they found that people with learning disabilities were less likely to have negative feelings about the abuse and were more likely to believe that someone else had the right to decide when they engaged in sexual activity. By increasing an individual’s knowledge about appropriate sexual expression and sexual rights, the sexual vulnerability of people with learning disabilities should be reduced. This view is supported by Craft (1993) who states that sex education has an important part to play in the prevention of sexual abuse in that it:

♦ Provides a context of what is ordinary and usual within sexual relationships;
♦ Gives individuals a vocabulary about body parts, feelings and sexual behaviour;
♦ Provides a forum for talking about and validating what individuals like and do not like;
♦ Includes work on self esteem and personal safety;
♦ Identifies people who will listen and take an individual’s worries and anxieties seriously;
♦ Empowers people.

However, not everyone shares the view that sex education reduces the incidence of sexual abuse amongst people with learning disabilities. Whitehouse & McCabe (1997) state that there is no evidence in the literature that sex education actually decreases the vulnerability of people with learning disabilities to sexual abuse. It is however, important to bear in mind that the secrecy often surrounding sexual abuse, coupled with individual’s lack of knowledge that
they are in an abusive situation, makes this a difficult hypothesis to test.

1.1.2. The Constituents of a Good Sex Education Programme

Craft (1994) states that people with learning disabilities have a right to as broad a sex education as possible, and in particular, should be taught about socially appropriate sexual behaviour, the possible consequences of sexual behaviour and how to deal with these, and how to recognise and respond to abusive situations. As well as increasing factual knowledge about sex and sexuality, sex education programmes also need to focus on people's feelings, attitudes, beliefs and values about sex. This means that issues possibly viewed by others as controversial or taboo also need to be included in the programme, for example, sex outside of marriage, promiscuity, abortion, HIV/AIDS, and gay and lesbian relationships (Craft, 1994). By adopting such an approach sex education programmes will hopefully be non-judgemental and will therefore not alienate members of the group who may for example be gay or who may be engaging in casual sexual relationships. It will also encourage the group participants to explore and challenge their views and beliefs on different sexual issues. In addition to this, sex education programmes also need to be mindful of the ability level, age and social circumstances of the participants. Taking all of these factors into account, it would appear that a good sex education programme should not be too prescriptive or adopt too narrow a focus. Ideally the agenda for the sex education programme should be based on areas of identified need and should be adapted to the ability level and ages of the course participants. This highlights the importance of a thorough assessment procedure at the outset of the sex education programme which can then inform the agenda for the programme.

Table One gives a summary of three published articles on sex education programmes and notes whether the above issues were taken into account.
### Table One  Summary of three published sex education programmes

<table>
<thead>
<tr>
<th>Study</th>
<th>Assessment carried out?</th>
<th>Type of assessment</th>
<th>Course contents</th>
<th>Length of course</th>
</tr>
</thead>
<tbody>
<tr>
<td>McDermott, Martin, Weinrich &amp; Kelly (1999)</td>
<td>Yes</td>
<td>‘Social Sexual Assessment’, 148-item questionnaire</td>
<td>Based on a manual and individualized for each participant. 13 possible areas: self-esteem, relationships, decision making, bodily functions, hygiene, exercise &amp; physical fitness, coping with stress &amp; anger, nutrition, alcohol, tobacco &amp; drug avoidance, exploitation, abuse &amp; crime prevention, understanding &amp; proper use of birth control, prevention of sexually transmitted diseases, health care consumerism</td>
<td>1 year</td>
</tr>
<tr>
<td>Lindsay, Belshaw, Culross, Staines &amp; Michie (1992)</td>
<td>Yes</td>
<td>Based on that published by Fisher et al. (1973) covering 7 areas: Identification of body parts, masturbation, puberty, intercourse, pregnancy &amp; childbirth, birth control, venereal disease.</td>
<td>Followed the course of “Sexuality Education for the Lower Functioning Mentally Handicapped” (Concord Films Council Ltd, Ipswich, England). Covering identification of body parts, puberty, social relationships, human reproduction, birth control, venereal disease &amp; marriage. Supplemented with films on pregnancy and role plays on asking people out, saying “no” to strangers &amp; friends and accepting invitations for a date.</td>
<td>9 months</td>
</tr>
<tr>
<td>Penny &amp; Chataway (1982)</td>
<td>Yes</td>
<td>Sexual Vocabulary Test</td>
<td>Identification of body parts, reproduction, sexual interactions, contraception &amp; sexually transmitted diseases.</td>
<td>6 weeks</td>
</tr>
</tbody>
</table>

All three programmes utilised assessments on sexual knowledge prior to the sex education programme. It is unclear though, if the information provided by the assessments was used to structure the contents of the programme or whether the programme followed a set format. It
would appear that at least two of the programmes (Lindsay et al., 1992; Penny & Chataway, 1982) followed a pre-existing format. All three of these programmes focussed on increasing levels of sexual knowledge, but again it is unclear if time was spent exploring participants’ beliefs, feelings and values about sexuality and relationships or whether issues such as homosexuality, promiscuity and abortion were discussed.

Although there are some generally agreed ideas of what constitutes a good sex education programme, it is clear from the published accounts mentioned above that programmes offered to people with learning disabilities vary considerably in terms of the assessment measures used, the course content and the length of the programme. It is also clear from perusal of the published studies that few sex education programmes are adequately evaluated. Evaluation of sex education programmes is paramount if we are to ensure that people with learning disabilities have been equipped with and have retained the necessary information and skills needed to be able to lead fulfilled and safe sexual lives.

1.1.3. The Evaluation of Sex Education Programmes

Whitehouse and McCabe (1997), in relation to sex education programmes, state that “most of the programs are hampered by methodological problems; they either fail to evaluate the effectiveness of the program or use inadequate measures or controls” (p. 233). There are a number of reports in the literature attesting to the effectiveness of sex education programmes. However, these claims are either not supported by any evaluative data or the outcome data provided is not detailed enough to critically evaluate the efficacy of the programmes (for examples of these studies see Jacobs, Samowitz, Levy & Levy, 1989; Kempton, 1987; O’Day, 1988; Ragg & Rowe, 1991; Thaler & Green, 1983; Walker-Hirsch & Champagne, 1986). Although these studies provide a convincing subjective account of the success and efficacy of the sex education programmes, without the inclusion of adequate evaluative data it is unclear to the reader if the programmes did in fact achieve their aims.

A number of published reports of sex education programmes have included information on
outcome and provide detailed evaluation data. These accounts tend to fall into two
categories: those that have used a traditional pre and post group questionnaire (for example
Lindsay et al., 1992; Penny & Chataway, 1982 & Robinson, 1984) and those that have used
more innovative evaluation techniques such as confirmatory factor analysis (for example
McDermott, Martin, Weinrich & Kelly, 1999) or qualitative content analysis (for example
Lawrence & Swain, 1993).

Penny & Chataway (1982) carried out a six-week sex education programme as described in
table one. They used the ‘Sexual Vocabulary Test’ to assess participants’ level of knowledge
prior to and after completion of the course. It was found that participants’ sexual vocabulary
increased following attendance at the group. Although sexual vocabulary increased, no
assessment was made of whether sexual knowledge in general increased; whether this
influenced the sexual behaviour of participants in any way or even whether the participants
were able to use the words they had learnt in a meaningful way. Without this information it is
difficult to know what the exact aims of this programme were and therefore whether the aims
of the programme were achieved.

Two studies employing a more robust research methodology by use of a control group, are
those of Robinson (1984) and Lindsay et al. (1992). Robinson (1984) measured changes in
both sexual knowledge and sexual attitudes following a sex education programme using the
‘Socio-Sexual Knowledge and Attitudes Test’ (SSKAT). It was found that the experimental
group had significantly more knowledge about sexual issues following the course than did the
control group. No information was provided though on whether knowledge in specific areas
increased more than others. In terms of sexual attitudes, Robinson compared the mean scores
from the ‘SSKAT’ for the control group and experimental group. It was found that at the end
of the programme the experimental group had higher scores than the control group. However,
no statistical test was carried out to see if the difference in mean scores was statistically
significant. Additionally, no information was provided on interesting trends such as whether
those in the experimental group with more negative attitudes prior to the course developed
more positive sexual attitudes as a consequence of the course.
Lindsay et al. (1992) carried out pre-and post-course assessments on 46 participants and a control group of 14 individuals. This covered seven areas as described in table one. The participants were split into groups of about six and attended a nine-month sex education programme. The pre-course assessments showed no difference in sexual knowledge between the experimental group and the control group. The post-course assessments however, showed that the experimental group had a significantly higher level of sexual knowledge than did the control group. Lindsay et al. repeated the assessments three months after completion of the programme to investigate whether the newly acquired knowledge was retained over time. It was found that at three month follow up the experimental group had retained their level of knowledge. One minor difficulty with the follow up measure is that only 23 of the original 46 participants were re-assessed. It is unclear, therefore, if their results would be representative of the group as a whole. Although methodologically sound, Lindsay et al.’s study, like the others, was not able to provide a measure of how people translated what they had learnt in the programmes into their everyday lives. Such a measure would be invaluable in evaluating how participants use the information they have learnt during the sex education programme.

Lawrence & Swain’s (1993) sex education programme had two specific aims. The first was to provide participants with access to information and facts concerning sex and sexuality, which had been traditionally denied them. The second was to promote greater self-confidence in the participants concerning their own sexuality. To evaluate whether the course achieved its aims certain sessions were audio-taped and transcribed. Examples of the appropriate use of key words were then noted. To evaluate whether participants had achieved a greater level of self-confidence related to their sexuality, Lawrence & Swain looked for examples in the transcripts of occasions where participants were able to talk about sexual issues with a degree of openness and honesty. An example of this approach is given below:

Teacher: OK we were talking about the changes that happen inside a woman’s body during adolescence and we talked about the eggs. Where do the eggs come from?
Mickey: Inside the body in a special place at the top of the fropian [sic] tube.
Teacher: The fallopian tube, that’s right but where do they go?
Although Lawrence & Swain give a detailed account of the evaluation method used, and provide data from the transcription, it is unclear whether the programme actually achieved its aims. This is an innovative and interesting approach to evaluation although not without its weaknesses (some of which are conceded by Lawrence & Swain). The biggest drawback is that transcriptions only give an account of more vocal participants' progress. In this way the progress of less vocal participants cannot be monitored or evaluated.

McDermott, Martin, Weinrich & Kelly (1999) evaluated a sexual education and health promotion programme (as described in table one) for 252 women with a learning disability. They did this by administering the ‘Social Sexual Assessment’ pre course and then again one year following the commencement of the programme. This asks questions in four domains: hygiene, social interaction, sexual behaviour and sexual knowledge. Confirmatory factor analysis\(^1\) was then used to explain the pathways of learning and the factors that contributed to changes in sexual knowledge. It was found that three factors: hygiene, social interaction, and sexual experience affected sexual knowledge directly i.e. women who took care of their hygiene, had some experience with sex and had positive social interactions were more likely to have a better sexual knowledge. It was also found that increases in sexual knowledge were related to a greater number of instructional contacts. McDermott et al. claim that the success of their programme is related to the understanding of the factors that contribute to changes in sexual knowledge, which allows them to modify their programme accordingly. The strength of McDermott et al.'s programme is that it not only focuses on sex education but also on the factors which can affect sexual knowledge and sexual behaviour. However, as the programme offers individualized training sessions over a one-year period, rather than group sessions, it would have serious cost implications for services.

\(1.\) Confirmatory factor analysis allows variables that are non-normally distributed to be used to explain the relationship between different factors, in this case hygiene, social interaction, sexual behaviour and sexual knowledge.
Despite differences in design and methodological weaknesses, the above studies go some way in demonstrating the efficacy of sex education programmes for people with learning disabilities. The majority of these studies have taken as their focus increases in sexual knowledge or understanding of sexual vocabulary, with only a few studies exploring changes in participants' sexual attitudes or interpersonal skills. Little emphasis has been placed in these studies on how participants use the knowledge they have acquired or how this might impact more generally on their behaviour. This remains a challenge for future outcome studies.

1.1.4 Aims of the Present Sex Education & Relationships Group

Based on the key points arising from a review of the literature it was decided that there would need to be a number of essential components to the current sex education programme i.e. understanding of sexual abuse, appropriate expression of sexuality, and understanding of safer sexual practices. At the same time the literature highlights the need for space within sex education programmes to address the individual needs of the men referred. As such, the content of the programme was shaped, as much as possible, by the results of the initial assessment (this will be discussed in more detail in the methods section). The literature also points to the need to focus not only on increasing participants' sexual knowledge but also on exploring attitudes, values and beliefs about sex and relationships. To this end, a decision was taken at the outset that the programme would not be overly didactic in nature but would encourage course participants to share their views and beliefs with each other. To assist in this it was decided that issues such as lesbian and gay sexuality, abortion and promiscuity would be included in the course content.

With these factors in mind it was decided that the aims of the current sex education programme should be to:
• Increase participants’ knowledge on sexuality and relationship issues,
• Develop participants’ general interpersonal skills,
• Provide the opportunity for participants to question and develop their beliefs and attitudes about sexual issues,
• Develop participants’ awareness of safer sexual practices,
• Provide the opportunity for participants to discuss issues of importance to them.
1.2. Method

1.2.1. Participants

Nine men were assessed for the sex education programme. Eight of these had been referred by a housing provider for people with learning disabilities. The main reason for referral was concern that some of the men were showing sexually inappropriate behaviour such as touching female care staff inappropriately. Care staff thought this was linked to a lack of understanding of appropriate sexual behaviour. Concern was also expressed that a number of the men were known to be engaging in sexual activities and staff were keen to ensure that they had an understanding of safer sexual practices. The remaining man was already known to the author. He was a married man and had been asking for information on contraception and safer sexual practices.

Of the nine men, seven lived in semi-supported community accommodation, one lived in a 24-hour staffed community care home and one lived independently with his wife. The men’s ages ranged from 24 years to 54 years with a mean age of 38 years. All of the men had a mild to moderate learning disability and were able to express themselves verbally.

All of the men referred were assessed prior to the start of the programme, according to the procedure described below. At this stage two men decided that they did not wish to attend the programme. Two more men dropped out of the programme after attending the first session. These men were met by the author to discuss their reasons for not wishing to continue with the group. Where necessary they were referred to the community team for people with learning disabilities for individual work. The remaining five men all completed the ten-week course.

As the sex education programme was part of routine clinical work rather than a research study it was decided not to use a control group. Use of a control group would have necessitated registering the group as a research study with the NHS Trust’s Research & Development
Department and would have required ethical approval.

1.2.2. Assessment Procedure

Sexual Knowledge

The assessment tool used was an unpublished questionnaire of sexual knowledge developed by the service in which the author worked (see Appendix One). As such it was not a standardised measure and had no normative data. However, it covered a broad range of sexual and relationship issues and had been successfully used by colleagues of the author to assess the sexual knowledge of people with learning disabilities. This is a 49 item questionnaire and asks questions in the following eight areas:

- Different types of relationships (e.g. husband/wife, friend)
- Menstruation
- Pregnancy
- Sexual Intercourse
- Masturbation
- Contraception & Abortion
- HIV/AIDS and other Sexually transmitted diseases
- Homosexuality

In addition, the questionnaire asks individuals to identify different parts of the body from line drawings of a naked woman and man.

The assessment is scored by allocating two points to a correct and full answer and one point to an incomplete answer or one that is broadly correct although not exact. This means that participants could score a maximum of 112 points.

All participants were assessed prior to the course commencing, and for those who completed
the course, again following the end of the programme. As time constraints meant that assessments could not be repeated immediately following the end of the programme and again at three-month follow-up (as in Lindsay et al’s. (1992) study), it was decided at the outset to delay the repeat assessment until three months after the end of the programme.

Each participant was interviewed by the author and the co-facilitator of the sex education programme, a male community nurse. The assessments took place either at the men’s homes or at the community team office where the facilitators were based. As the questions could be embarrassing for the participants, time was spent beforehand establishing a rapport with them. The answers to the questions were written down verbatim. If it was thought that the participant knew the answer to a question but was reluctant to give an answer, they were given prompts and encouragement. The questionnaire took about 30 minutes to complete.

After administering the questionnaire, time was spent talking with the men about specific issues they would like to have addressed in a sex education programme. These are outlined in Appendix Two.

Measurement of Course Aims

In addition to measuring changes in sexual knowledge, it was necessary to look for evidence that other course aims had been achieved. This was done by scrutinising the process notes from each session. As the group sessions were not audio-taped and only brief process notes were made, it was not possible to carry out a more formal qualitative analysis of the data.

At the end of the course, participants were also asked to give verbal feedback on what they had found most useful about the sex education programme and areas they would like to have addressed in more detail.
1.2.3. Procedure

Development of the Sex Education Programme Content

Once the initial assessments had been completed and scored, the course facilitators used the results to draw up an agenda for the sex education programme. Areas of the assessment where the men had scored less well i.e. menstruation, pregnancy, masturbation, contraception and sexually transmitted diseases were given priority. As suggested by the literature review, time was also scheduled into the programme to discuss the issues of sexual abuse and appropriate expression of sexuality. Although the men scored relatively well on identification of male body parts it was decided to include this in the first session in order to ensure that the group had a common language for discussing sexual issues throughout the programme. Where possible, issues that the men had asked to have addressed (Appendix Two) were scheduled into the course content.

The content of each session is summarised in Table Two and a more detailed account can be found in Appendix Three.

Table Two Outline of sessions

<table>
<thead>
<tr>
<th>Session</th>
<th>Topic</th>
</tr>
</thead>
<tbody>
<tr>
<td>One</td>
<td>Ground rules, identification of body parts</td>
</tr>
<tr>
<td>Two</td>
<td>Bodily functions, puberty &amp; menstruation</td>
</tr>
<tr>
<td>Three</td>
<td>Different types of relationships</td>
</tr>
<tr>
<td>Four</td>
<td>Sexual abuse, good/bad touch, consent</td>
</tr>
<tr>
<td>Five</td>
<td>Good/bad touch, legal aspects of sexuality</td>
</tr>
<tr>
<td>Six</td>
<td>Consent and choice in sexual relationships</td>
</tr>
<tr>
<td>Seven</td>
<td>Masturbation</td>
</tr>
<tr>
<td>Eight</td>
<td>Sexual activities, pregnancy</td>
</tr>
<tr>
<td>Nine</td>
<td>Contraception, safer sex</td>
</tr>
<tr>
<td>Ten</td>
<td>HIV &amp; AIDS, general recap'</td>
</tr>
</tbody>
</table>
Session Format

The sex education course took place once a week for ten weeks. The sessions took place in a community resource centre, easily accessible for all the participants. Each session lasted for one and a half hours and commenced with tea and biscuits and a general chat. This allowed time for latecomers to arrive and also gave the participants an opportunity to socialize with, and get to know each other.

The sessions always followed the same format:

- A warm up exercise,
- The main topic of discussion,
- An ending game.

The sessions were a mixture of large group discussions, small group exercises, games, role-plays, videos and practical exercises e.g. learning to put a condom onto a model penis. Although the facilitators devised the activities themselves, they were informed by a number of sex education resources for people with learning disabilities, most notably ‘Sex and The Three R’s: Rights, Responsibilities and Risks’ (McCarthy & Thompson, 1993).

At the end of each session the facilitators would discuss the progress of the group and key themes and observations would be documented in the process notes.
1.3. Results

1.3.1. Assessment of Sexual Knowledge

Table Three shows the total scores obtained by each participant on the assessment of sexual knowledge both prior to the sex education programme and again at three-month follow-up. In all cases, total scores had increased following participation in programme - the smallest increase being 9 points and the greatest 31 points (mean = 19). Taking the combined scores of all participants there was an overall increase in sexual knowledge scores of 95 points. A paired samples T-Test carried out on the scores showed that differences were statistically significant (t = 5.418, p< 0.01). These results indicate that overall, the programme achieved its aim of increasing participants' level of sexual knowledge. Moreover, the results also show that new knowledge acquired in the programme was retained at three-month follow-up.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Total Pre-Course Score</th>
<th>Total Post Course Score (3 month follow-up)</th>
<th>Difference in Scores</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>41</td>
<td>72</td>
<td>31</td>
</tr>
<tr>
<td>2</td>
<td>32</td>
<td>50</td>
<td>18</td>
</tr>
<tr>
<td>3</td>
<td>54</td>
<td>73</td>
<td>19</td>
</tr>
<tr>
<td>4</td>
<td>76</td>
<td>94</td>
<td>18</td>
</tr>
<tr>
<td>5</td>
<td>37</td>
<td>46</td>
<td>9</td>
</tr>
<tr>
<td>Total</td>
<td>240</td>
<td>335</td>
<td>95</td>
</tr>
</tbody>
</table>

To see if knowledge scores increased over all ten categories of the sexual knowledge assessment, further comparisons of pre and post course scores were carried out. The results from these are shown in Table Four. Again, scores increased for all categories of the assessment - the smallest change being 2 points for ‘sexual activities and sexual intercourse’ and the greatest 32 points for ‘HIV/AIDS and sexually transmitted diseases. Although scores increased over all ten areas of the assessment, paired samples T-Tests
indicated that these changes were only statistically significant for three categories, namely: 'HIV/AIDS and sexually transmitted diseases' ($t = -4.46$), 'menstruation' ($t = -4.22$), and 'identification of female body parts' ($t = -3.21$). One possible explanation for this is that pre-course scores (and therefore level of knowledge) for these categories were lower than those for other categories e.g. the pre-course score for 'menstruation' was 17 out of 60 whereas for 'relationships' it was 34 out of 60.

### 1.3.2. Development of Interpersonal Skills

In terms of developing interpersonal and social skills two main issues were noticed from perusal of process notes. In the early stages of the group participants found it difficult to talk directly with each other. Communication was mostly directed to the group facilitators, even when it was suggested that the views of other group members should be sought. Another difficulty experienced at this stage was the men’s tendency to talk over one another instead of taking turns to speak. However, through the enforcement of ground rules and continued encouragement to ask each other questions, the men were much more confident, by the end of the ten sessions, in discussing issues with each other and in offering advice to each other. They were also much more able to take turns in speaking and were interrupting each other more appropriately.

Another example of improvement in interpersonal skills came from the men’s interactions with one particular group member. This man would initially dominate discussions and would very quickly begin to talk about unrelated issues. Although in early sessions the men found this difficult to tolerate and would make inappropriate and upsetting comments to him, by the end of the ten sessions they were able to remind him appropriately that he was talking too much. In turn, he was more able to tolerate their suggestions that someone else should be allowed to speak and even began to notice occasions when he had been dominating the discussions.
1.3.3. Development of Beliefs and Attitudes about Sexual Issues

All participants were encouraged to discuss their attitudes and beliefs about sexuality and relationships openly throughout the course, even if these were contrary to the majority view. This was highlighted by one participant in particular. Whereas all other group members thought that lesbian and gay sexuality was acceptable he did not share this view. He was encouraged to explore this belief by the other participants, and although it is unclear if his views changed, he stated that he had found it useful discussing this issue.

Another example of group members developing their beliefs and attitudes arose out of a discussion on older people engaging in sexual activity. All participants initially believed that older people, especially those over the age of 60, would no longer have sex. The discussion which ensued enabled the men to challenge and modify this belief.

1.3.4. Awareness of Safer Sex

Increased awareness of safer sexual practices can be seen from the significant increase in scores in the area of ‘HIV/AIDS and sexually transmitted diseases’ on the assessment of sexual knowledge. All men also had the opportunity to practise putting condoms onto a model penis. All except one participant, who was too embarrassed to try this, were able to do this competently by the end of the training session.

1.3.5. Opportunities for Participants to Discuss Issues of Personal Importance

In terms of having an opportunity to discuss their own sexual and relationship issues, scrutiny of process notes indicated that all participants spoke at some point during the sessions about issues pertinent to themselves. Issues raised included relationship difficulties with a partner, appropriate places to meet other men for sex, pain experienced during sexual activity and sexual abuse in childhood.
1.3.6. Participants' Feedback

At the end of the final group all participants were asked for their feedback on the sex education programme. All stated that they had found it interesting and listed the following as issues they had found particularly useful:

- Discussions about men having sex with men,
- Watching “Piece by Piece” - a video using anatomically correct puppets to explain safer sex and sexual practices,
- Practising how to use condoms,
- Discussions on HIV/ AIDS.

Other feedback given about the course was that it would have been useful to have had more discussions on mixed race relationships and men having sex with men in public places.
<table>
<thead>
<tr>
<th>Category</th>
<th>Total pre-course score for all participants</th>
<th>Total post-course score for all participants</th>
<th>Difference in scores</th>
<th>Maximum possible score for category</th>
<th>T-Value</th>
<th>Significance level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationships</td>
<td>34</td>
<td>42</td>
<td>8</td>
<td>60</td>
<td>-1.24</td>
<td>0.282</td>
</tr>
<tr>
<td>Menstruation</td>
<td>17</td>
<td>31</td>
<td>14</td>
<td>60</td>
<td>-4.22</td>
<td>0.013*</td>
</tr>
<tr>
<td>Pregnancy</td>
<td>31</td>
<td>34</td>
<td>3</td>
<td>70</td>
<td>-.885</td>
<td>0.426</td>
</tr>
<tr>
<td>Sexual activities &amp; sexual intercourse</td>
<td>11</td>
<td>13</td>
<td>2</td>
<td>20</td>
<td>-1.00</td>
<td>0.374</td>
</tr>
<tr>
<td>Masturbation</td>
<td>33</td>
<td>46</td>
<td>13</td>
<td>90</td>
<td>-1.857</td>
<td>0.137</td>
</tr>
<tr>
<td>Contraception &amp; abortion</td>
<td>22</td>
<td>25</td>
<td>3</td>
<td>60</td>
<td>-.452</td>
<td>0.675</td>
</tr>
<tr>
<td>HIV/AIDS &amp; STDs</td>
<td>33</td>
<td>65</td>
<td>32</td>
<td>100</td>
<td>-4.459</td>
<td>0.011*</td>
</tr>
<tr>
<td>Homosexuality</td>
<td>18</td>
<td>20</td>
<td>2</td>
<td>20</td>
<td>-1.00</td>
<td>0.374</td>
</tr>
<tr>
<td>Identification of body parts (Female)</td>
<td>20</td>
<td>32</td>
<td>12</td>
<td>40</td>
<td>-3.207</td>
<td>0.033*</td>
</tr>
<tr>
<td>Identification of body parts (Male)</td>
<td>21</td>
<td>27</td>
<td>6</td>
<td>30</td>
<td>-1.195</td>
<td>0.298</td>
</tr>
</tbody>
</table>

(* = Significant at the .05 level)
1.4. Discussion

Overall, the aims of the sex education programme were achieved. In terms of sexual knowledge there was a statistically significant increase in participants’ level of knowledge overall. Although scores increased over all ten categories of the assessment this was only statistically significant for three areas namely ‘menstruation’, ‘HIV/AIDS and sexually transmitted diseases’ and ‘identification of female body parts’. When the pre-course scores for the other categories are looked at it can be seen that these are relatively high, especially for ‘homosexuality’ and ‘male body parts’, suggesting existing knowledge in these areas.

Other possible reasons why changes in scores may not have been statistically significant for all areas are that not enough time was spent focusing on these issues in the programme, or that the information provided was too complex for the men to understand. As the post course assessments were carried out three months following the end of the programme it may also be the case that the men did have a better understanding of these issues directly following the group but this was not retained over time. This highlights the need, as in Lindsay et al’s. (1992) study, for assessments to be carried directly following the group and again at three month follow-up. If it was found that knowledge scores were higher directly following the course this would indicate the need for regular refresher courses to help the men retain and consolidate the information they had learnt.

That pre-course knowledge in the area of ‘female body parts’ and ‘menstruation’ were lower is hardly a surprising finding. It is unlikely that the men would have been previously taught about these issues. What is surprising is the magnitude of the increase in knowledge in these areas, and the fact that this was maintained at three-month follow-up. This is a reassuring finding, especially for the group members in heterosexual relationships as this information will hopefully make them more aware of, and sensitive to, their partner’s needs. There was also a highly significant difference in scores pre-and post-course in the area of ‘HIV/AIDS and sexually transmitted diseases’. This perhaps reflects the amount of time spent discussing these issues in the programme. The facilitators were mindful that several of the men were
either in long term sexual relationships or engaged in casual sex and were therefore keen to ensure that all participants had a good understanding of safer sexual practices. In addition all of the men appeared very interested in this area, indeed some participants knew people who had HIV or who had died as a consequence of HIV infection.

There was also clear evidence from perusal of process notes that the other course aims had been achieved. There was evidence of increased social and interpersonal skills within a group setting; evidence that course participants had been given the opportunity to explore and develop their beliefs and attitudes about sexuality; and evidence that the men had discussed issues pertinent to them. All of the men, with one exception, also demonstrated the ability to use condoms appropriately.

There were a number of limitations to this sexuality and relationship course. In terms of the evaluation process, there was no control group with which to compare results. However, in practice it is often very difficult, both in terms of time constraints and ethical considerations, to employ a control sample for routine clinical work. As in previous evaluation studies, the current programme only included an evaluation of sexual knowledge. No evaluation took place of how group members used the knowledge they had learnt and if indeed increase in sexual knowledge led to changes in sexual behaviour. This is a particularly pertinent issue for this sex education programme, as men were initially referred because of concerns that they were engaging in sexually inappropriate behaviours. Interviews with care staff could have been carried out following the programme to ascertain if these sexually inappropriate behaviours had decreased. Finally, as McDermott et al. (1999) found that increases in sexual knowledge were highly correlated to number of instructional contacts, it may be worth considering running any future sex education programmes over a longer period of time.

1.4.1. Conclusion

As in previous evaluations of sex education programmes, the current evaluation has shown that participants can benefit from a ten-week sexuality and relationship course and that
information learnt in the course can be retained over time. One issue that remains unclear however, is the use to which men with learning disabilities put the knowledge they have learnt. For example, are the men less likely to engage in sexually inappropriate behaviour following a sex education programme and are they more able to develop safe and satisfying sexual relationships?

Although services are often keen for those in their care to attend sex education courses there is often a reluctance to provide opportunities and support to people with learning disabilities in developing sexual relationships with a partner of their choice. As well as focusing on sex education programmes for people with learning disabilities, professionals also need to consider providing support and training to carers so that they are equipped to support people with learning disabilities in developing and maintaining safe, meaningful and fulfilling sexual relationships.
1.5. REFERENCES


Appendix One

Assessment Questionnaire for Sexuality and Relationship Course
I’m going to ask you some questions and the meanings of some words. For some of those words I am going to ask more detailed questions. Do you have anything you would like to ask me before we begin?

The words in brackets should be used if the individual does not understand the word used.

(Use prompts such as: tell me more about that. Please explain that further)

Relationships

1. What is a friend?
2. What is a boyfriend/girlfriend?
3. What is a husband/wife?
4. What is a relationship?
5. What is a lover?
6. What is the difference between a boyfriend/girlfriend and a friend?

Menstruation

7. What is an ovum? (Woman’s egg)
8. What is a period? (Time of the month)
9. How often do women have periods?
10. Do men have periods?
11. What is a sanitary towel?
12. What is a tampon?

Pregnancy

13. What does the word pregnant mean?
14. How does a woman get pregnant?
15. How does a woman know she is pregnant
16. How long does it take from getting pregnant to the baby being born?
17. Where does the baby grow?
18. Where does the baby come out?
19. Are there any times a woman cannot become pregnant?

Sexual Intercourse

20. What is sexual intercourse?
21. What happens during sex?
Masturbation

22. What is sperm? (Spunk, come)
23. What is an orgasm?
24. What is masturbation?
25. Do you know how a man masturbates?
26. Can you tell me how a man masturbates?
27. Do you know how a woman masturbates?
28. Can you tell me how a woman masturbates?
29. Why do people masturbate?
30. What is a wet dream?

Contraception and Abortion

31. How do you prevent pregnancy?
32. What is contraception?
33. What is sterilisation?
34. What is a condom? (Sheath, rubber, Johnny)
35. What is the pill?
36. Condoms, the pill and sterilisation are all ways of stopping pregnancy. Which are the best?
37. What does abortion/termination mean?

HIV/AIDS and Sexually Transmitted Diseases

38. What is HIV?
39. What is AIDS?
40. How do you get HIV/AIDS?
41. How can you stop HIV/AIDS?
42. Can you get diseases through sex?
43. What is VD? (The clap)
44. What would you do if you got a disease from having sex?
45. How would you know if you had got a disease from having sex?
46. Which contraceptives can prevent them?
47. How would you stop yourself getting one?

Homosexuality

48. What does homosexual mean? (Gay, queer, poof)
49. What does lesbian mean? (Dyke)

Are there any questions you would like to ask me?
Now turn to the drawings of the naked man and woman and ask the individual to identify the body parts indicated.
Q: Please name the body parts indicated.
Q: Please name the body parts indicated.
Appendix Two

Issues the group participants wanted the course to address

♦ Sexually transmitted diseases
♦ Homosexuality and transvestism
♦ Making love and different sexual activities
♦ Trust within relationships and consent
♦ Virginity and religious beliefs about sexuality
♦ Prostitution
♦ Pregnancy and childbirth
♦ Forming relationships and where to meet people
♦ Safer sex and contraception
♦ Good and bad touch
♦ Relationships and inter-racial relationships.
Appendix Three
Outline of Ten-Week Sexuality and Relationship Course

Week 1. Development of ground-rules for the group. Labelling parts of the body on a large drawing of a man and women (both sexual and non-sexual). Agreement on a common language for different parts of the body.


Week 3. Different types of relationships people can have (e.g. friends, family, intimate) and what makes these relationships different to each other. Gay and lesbian relationships. Why people have friends and boy/girlfriends.

Week 4. Examples of good and bad touch, consent and what to do if you are touched inappropriately.

Week 5. Legal aspects of sexuality: age of consent, prostitution, appropriate environment for sexual contact. Where to meet other people and role-play of asking people out.

Week 6. Watching video “My choice my own choice” about deciding when to have a sexual relationship with a partner. How to negotiate sexual issues with a partner e.g. consent to different sexual activities, expressing your desires and contraception.


Week 8. Different sexual activities couples can engage in (both heterosexual and homosexual). Video: “Piece by Piece” using puppets to show different sexual activities. Pregnancy: Which sexual activities can lead to pregnancy, what happens when a woman becomes pregnant and childbirth.

Week 9. Contraception: why it is needed, different types, condoms. Condom training kit: putting condoms on a model penis. Sexually transmitted diseases: how to recognise them and what to do about them.

Week 10. HIV and safer sex. What HIV is and how it is transmitted and who is at risk. High and low risk sexual activities and use of condoms. Recap’ of previous nine sessions and feedback from participants.
CRITICAL REVIEW ONE

Difficulties in the Diagnosis of Alzheimer's Disease in People with Down's Syndrome
2.0. Introduction

"In not a few instances, however, death was attributed to nothing more than general decay- sort of precipitated senility"

Fraser & Mitchell (1876)

In this quotation Fraser and Mitchell are describing the cause of death in people with Down’s Syndrome. This is thought to be the first documented account of the now well established link between Down’s Syndrome and dementia. Several years later Struwe (1929) described the characteristic plaques of Alzheimer’s disease in the brains of individuals with Down’s Syndrome and by 1977 Heston argued, based on post mortem data, that all people with Down’s Syndrome over the age of 35 had the neuropathological markers of Alzheimer’s disease i.e. neurofibrillary tangles and neuritic plaques.

Since that time a great deal of research has been carried out examining the links between these two disorders. In part this has reflected the fact that as medical science has advanced so the life expectancy of people with Down’s Syndrome has increased. In 1929 the estimated life expectancy of individuals with Down’s Syndrome was 9 years. This rose to 18.3 years in 1961 (Penrose, 1963). Baird and Sadovnick (1988) estimate that 44 per cent of people with Down’s Syndrome alive today will live to the age of 60 and 13.8 per cent to the age of 68. As virtually all people with Down’s Syndrome over the age of 35 have the neuropathological features of Alzheimer’s disease it should follow that as life expectancy for people with Down’s Syndrome has increased so should the incidence of Alzheimer’s disease amongst this population. However, according to Lai and Williams (1989), clinical symptoms of Alzheimer’s disease are only present in 36 per cent of people with Down’s Syndrome over the age of 35. They state that the reason for this is poorly understood.

As individuals with Down’s Syndrome appear to have an increased risk of developing Alzheimer’s disease in later life it is important that any signs or symptoms of dementia
are detected early on so that appropriate treatment and care planning can take place. However, the diagnosis of Alzheimer’s disease in people with Down’s Syndrome is far from clear cut. Loss of functional and cognitive skills in people with Down’s Syndrome may be related to a treatable condition rather than dementia e.g. hypothyroidism or depression (Prasher & Krishnan, 1993). As people with Down’s Syndrome already have some cognitive deficits as a result of their learning disability, it is often difficult to establish a baseline level of skills from which to measure any deterioration. Even if a baseline level can be established there are as yet few cognitive assessments sensitive enough to measure change in this population, and fewer still that have been standardised on this client group.

This critical review will examine the literature on the diagnosis of Alzheimer’s disease in people with Down’s Syndrome from the perspective of differential diagnosis, effectiveness of neuro-imaging techniques and the efficacy and utility of existing cognitive assessments for detecting dementia in people with Down’s Syndrome.

2.1. Diagnostic Criteria for Dementia

Diagnosis of dementia in the general population is made based on the diagnostic criteria set down in either ‘The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition’ (DSM IV) (American Psychiatric Association, 1994) or ‘The International Classification of Diseases, Tenth Edition’ (ICD-10) (World Health Organisation, 1992). The criteria advised by both DSM IV and ICD-10 are shown in Appendices One and Two respectively.

Although both sets of criteria are similar (as one would expect), a working group for the ‘Establishment of Criteria for the Diagnosis of Dementia in Individuals with Intellectual Disability’ (Aylward, Burt, Thorpe, Lai & Dalton, 1997) advocate the use of ICD-10 criteria over that of DSM IV. The main reason for this is that ICD-10 places more emphasis on non-cognitive aspects of dementia (i.e. emotional factors such as emotional lability, irritability and apathy), which are often the first signs of dementia in people with intellectual disability (Lai & Williams 1989; Evenhuis 1990). In addition ICD-10
suggests a two-step approach to diagnosis which initially establishes a diagnosis of dementia and then differentiates Alzheimer’s disease from other types of dementia. This is especially important in the diagnosis of dementia in people with Down’s Syndrome because of the increased risk from Alzheimer’s disease - there may be a tendency for mental health professionals to misdiagnose other types of dementia (e.g. multi-infarct dementia) as Alzheimer’s disease.

Effective and accurate diagnosis of dementia and Alzheimer’s disease in people with Down’s syndrome therefore needs to be based on the agreed definitions of these conditions as set out in ICD-10.

2.2. Differential Diagnosis

Both DSM IV and ICD-10 highlight the importance of differential diagnosis when assessing for dementia. This is particularly important in people with Down’s Syndrome who are more prone to certain physical and emotional/psychological conditions which may account for dementia type symptoms. As Trumble (1999) states, “the key to making the diagnosis of dementia in a person with Down’s Syndrome is the exclusion of other possible causes of functional deterioration” (p 50).

One of the most important differential diagnoses is between dementia and hypothyroidism (under-functioning of the thyroid gland). Up to 40 per cent of people with Down’s Syndrome meet the biochemical criteria for hypothyroidism at some point in their lives (Mitchell, Blachford, Carlyle & Clarson, 1994). However, the diagnosis of hypothyroidism in a person with Down’s Syndrome is made difficult by “gross similarities in both the conditions” (p 148) and may therefore go undiagnosed (Prasher, 1993). Fortunately, thyroid function tests are relatively easy to carry out and according to Trumble (1999) should be carried out routinely on an annual basis.

Sensory deficits (i.e. hearing and visual difficulties), which can again mimic the confusion, disorientation and deterioration in functional skills common to dementia, can occur at a higher rate in people with Down’s Syndrome. Haveman, Maaskant and
Sturman (1989) found twice the rate of visual problems and three times the rate of auditory problems in those with Down’s Syndrome over the age of 40 compared to the general population. It is important therefore that regular visual and hearing screenings are carried out for people with Down’s Syndrome in order to identify and rectify any difficulties.

People with Down’s Syndrome are also more susceptible to depression. However, communication difficulties may mean that this often goes undetected. Warren, Holroyd and Folstein (1989) report that five patients referred to them for the evaluation of dementia all had major depression, which was treatable, rather than Alzheimer’s disease.

As people with learning disabilities may not necessarily meet DSM IV criteria for depression, behaviour change is perhaps a better indicator of depression in this client group (Meins, 1996). An increase in challenging behaviours, decline in functional skills, irritability, weight change and sleep disturbance may all be indicators of depression rather than dementia. Fortunately, new scales for the detection of depression in people with learning disabilities such as that devised by Meins (1996) have greatly aided the diagnosis of depression in this client group. Trumble (1999) warns though that depression may also be an early indicator of dementia and therefore should not preclude a diagnosis of Alzheimer’s disease.

Differential diagnosis should not just be restricted to physical and psychological conditions. Trumble (1999) states that unexpected environmental change can often have a great impact on the cognitive and functional abilities of people with learning disabilities, even changes which are considered minor to others e.g. when a bus on which the person routinely travels takes a different route. It is therefore important when assessing for dementia to enquire about recent changes which might have occurred in the person’s life.

Table One outlines Trumble’s approach to differential diagnosis in people with Down’s Syndrome and specifies what needs to be done in order to rule out other possible causes of a person’s deterioration.
Table One The D.E.M.E.N.T.I.A. approach system in Down’s Syndrome adapted from Trumble (1999)

<table>
<thead>
<tr>
<th>Hypothesis</th>
<th>Key factors to consider</th>
<th>Action to take</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression &amp; other psychiatric problems</td>
<td>Signs may be subtle &amp; easily overlooked. Grief reactions are common</td>
<td>Careful history taking with special attention to organic signs of depression</td>
</tr>
<tr>
<td>Environmental problems</td>
<td>Includes changes to family or significant other people. Changes in living or work environment. Also internal environment (pain)</td>
<td>Wide ranging history with information from a variety of sources (family, accommodation staff, employment staff)</td>
</tr>
<tr>
<td>Malignancy</td>
<td>Especially gastro-intestinal or respiratory with brain secondaries.</td>
<td>Careful examination including a rectal, chest X-ray and possibly brain CT scan</td>
</tr>
<tr>
<td>Endocrine &amp; Metabolic</td>
<td>Hypothyroidism, Diabetes, Menopause, Vitamin B12, Vision</td>
<td>Thyroid function tests and other relevant blood tests</td>
</tr>
<tr>
<td>Neurological</td>
<td>Vision or hearing deficit, Spinal cord compression, Parkinson’s disease, Epilepsy</td>
<td>Ophthalmological &amp; audiological assessment, EEG &amp; neurology assessment</td>
</tr>
<tr>
<td>Toxin</td>
<td>Medications (especially benzodiazepines), Alcohol</td>
<td>Review medication list and access to alcohol</td>
</tr>
<tr>
<td>Infection</td>
<td>Particularly respiratory or urinary</td>
<td>Chest X-ray and urine specimen</td>
</tr>
<tr>
<td>Accident</td>
<td>Cerebrovascular accidents, Trauma (accidental &amp; non-accidental)</td>
<td>Careful history &amp; neurological examination. Speak with patient alone if possible. Consider CT brain scan</td>
</tr>
</tbody>
</table>

Differential diagnosis is not an easy task and can be time consuming. However it is a vital process if accurate diagnoses are to be made. It may also mean that people with Down’s Syndrome will be provided with the appropriate treatment for disorders that may mimic the symptoms of dementia and which may otherwise go undetected.
2.3. The Effectiveness of Neuro-Imaging Techniques in the Diagnosis of Dementia

In terms of differential diagnosis neuro-imaging techniques such as CT (computerized tomography) scans can be an invaluable tool, e.g. in the diagnosis of tumours and cerebrovascular accident. It is less clear however, how useful neuro-imaging techniques are in the actual diagnosis of dementia. Trumble (1999) states that reports from neuro-imaging techniques detailing non-specific findings such as cortical atrophy are too general to aid the diagnosis of dementia. Rabe, Wisniewski, Shupf and Wisniewski (1990) argue that it is not possible to distinguish the histo-pathological abnormalities in those individuals with Down’s Syndrome who demonstrate the clinical signs of dementia from those without the clinical signs. For this reason Aylward et al (1997) state that they do not advocate the confirmation of a diagnosis of Alzheimer’s disease in individuals with Down’s Syndrome through the use of histo-pathological analysis.

Several studies have now been conducted looking at the use of single photon emission tomography (Spet scans), magnetic resonance imaging (MRI scans), and electroencephalography (EEG) in the detection of Alzheimer’s disease in people with Down’s Syndrome with varying degrees of success.

2.3.1. The Use of Electroencephalography

Visser, Kuilman, Oosting, Overwig and Huffelen (1996) claim that electroencephalography (EEG) is an important tool in the clinical diagnosis of Alzheimer’s disease in patients with Down’s Syndrome, especially for those individuals who are not easy to assess cognitively (i.e. those with a more severe learning disability). They state that several studies indicate there may be a relationship between the mental deterioration of patients with Down’s Syndrome and an abnormal EEG pattern characterized by the absence of, or a very slow, alpha rhythm.

To examine the utility of EEG as a diagnostic tool for Alzheimer’s disease in people with Down’s Syndrome, Visser et al (1996) carried out a longitudinal study with 197 people with Down’s syndrome during a five to eight year period. During this time they monitored changes in EEG, especially to the alpha rhythm, and compared this with
changes to cognitive functioning as measured by a Dutch version of the ‘Cain-Levine Social Competence Rating Scale’ (Cain, Levine & Elzey, 1963). They also obtained carers’ permission to carry out post mortem neuropathological examination on patients who died during the study.

Scores on the measure of cognitive functioning did not decrease significantly for 162 of the 197 participants. In 29 participants there was a significant slowing of the alpha rhythm over time which was correlated to rate of deterioration in cognitive functioning. This finding was given further support by neuropathological examination. In eleven of the 29 patients who died during the study, abnormalities consistent with a severe form of Alzheimer’s disease were found. As further evidence of the utility of EEG in the diagnosis of Alzheimer’s disease in people with Down’s Syndrome, Visser et al. state that two male patients whose cognitive functioning and alpha rhythm remained relatively stable throughout the study also died. At post mortem examination some senile plaques were found but there were hardly any neurofibrillary tangles which would have been indicative of Alzheimer’s disease.

Although the results of this study appear promising the number of people involved is relatively small. However, strong support for the findings is provided by the post mortem examinations (as yet, the only accurate way of confirming a diagnosis of Alzheimer’s disease). In clinical settings the use of EEG in the diagnosis of Alzheimer’s disease may be limited as it is necessary to have a base line EEG recording before cognitive deterioration is first noticed to provide a comparator for successive recordings. For this reason Visser et al. (1996) strongly recommend that EEG recordings should be made for all patients with Down’s Syndrome before their mental functioning begins to deteriorate. This would of course have serious cost implications for learning disability services and would require a high level of compliance from people with Down’s Syndrome.

2.3.2. The Use of Single Photon Emission Tomography (SPET) Scans

Several studies have shown that there is an association between Alzheimer’s disease and changes in regional cerebral blood flow (rCBF) which can be shown using a SPET scan (Gemmell, Sharp, & Besson, 1987; Geaney, Soper, Shepstone & Cowen, 1990; Holman,
Johnson, Gerada, Carvalla & Satlin, 1992). There is also some evidence for an association between measurement of rCBF and cognitive performance (O'Brien, Eagger, Syed, Sahakian & Levy, 1992). To date few SPET studies have been carried out on people with Down's Syndrome, and those that have tend to be either individual case reports or have focused on a narrow age range. Only one study to date has used SPET scans in people with Down's Syndrome with early cognitive deterioration but without a clinical diagnosis of dementia (Jones, Kennedy, Hanson & Fenton, 1997).

Kao et al (1993) found rCBF abnormalities in all 14 of the people with Down's Syndrome they studied. However, as the age range for these people varied from 8 - 30 years - several years before the age one would normally expect to see clinical signs of Alzheimer's disease - it is unclear what these findings mean. This would tend to suggest that if rCBF abnormalities can be detected in the absence of clinical signs of dementia then SPET scans would prove little use in the diagnosis of Alzheimer's disease in people with Down's Syndrome. Further evidence for the lack of clinical utility of SPET scans comes from Jones, Kennedy, Hanson & Fenton (1997). They investigated 26 people with Down's Syndrome aged 16 - 55 years (mean age 39.2 years). They looked for a correlation between degree of dementia - as assessed by structured carer interview and perusal of case notes - and SPET scan abnormalities. Of the 26 participants five showed clear signs of clinical dementia, seven showed mild deterioration and 14 no deterioration. It was found that only one of the participants with a clear diagnosis of dementia had a rCBF abnormality which was consistent with this diagnosis. Moreover, three participants with mild deterioration and three with no deterioration also showed abnormal SPET scans, although these abnormalities were not consistent with a diagnosis of Alzheimer's disease.

Inconsistent findings from SPET scans would indicate that at the present time looking for abnormalities within rCBF of people with Down's Syndrome is not an effective or reliable way of diagnosing Alzheimer's disease in this population.
2.3.3. The Use of Magnetic Resonance Imaging (MRI)

Several studies have been carried out which have used MRI scans to investigate cognitive changes or Alzheimer's disease in people without learning disabilities (see Murphy, DeCarli & Daly 1993; O'Brien, Desmond, Ames & Schweitzer 1996), and to investigate differences between people with Down's Syndrome and those without (e.g. Weis, Weber, Neuhold & Rett 1991; Raz, Torres & Briggs 1995). Fewer MRI studies have been conducted looking at the differences between people with Down's Syndrome with and without a diagnosis of Alzheimer's disease i.e. MRI studies that would aid the diagnosis of Alzheimer's disease in people with Down's Syndrome.

Prasher, Barber, West and Glenholmes (1996) provide a case report on the neuropathological findings, as shown by MRI scan, in a 74 year old man with Down's Syndrome and a diagnosis of Alzheimer's disease. They state that their findings demonstrate that the MRI changes of marked cerebral atrophy and dilated lateral ventricles correlate with both the clinical and neuropathological findings of Alzheimer's disease in the Down's Syndrome population. However, the findings of this study would have to be viewed with caution as it is based on one case report with no control group. Additionally, as no base line MRI scan was carried out and the study was not longitudinal it is unclear whether the neuropathological findings were related to diagnosis of Alzheimer's disease or could have predated clinical signs of dementia. According to Pearlson et al. (1998) "many types of brain abnormalities have been described in individuals with DS both with and without dementia..." (p 326, italics added). Pearlson et al. also state that as neuropathological studies have not distinguished between brains of individuals with Down's Syndrome over the age of 40 and those under age 40 it is impossible to determine which effects are the result of normal aging and which are pathological and are therefore associated with Alzheimer's disease.

To address some of these issues Pearlson et al. investigated whether brain anomalies were uniform among people with Down's Syndrome and how brain anomalies varied between those people with Down's Syndrome with and without a diagnosis of Alzheimer's disease. Fifty participants took part in their study with a mean age of 42 (S.D= 10.45). Of
these 11 met the DSM IV criteria for dementia. They employed a control group of 23 people without Down’s Syndrome or learning disability who were all participants in a community study of normal aging. They found that participants with Down’s Syndrome compared to the control group had an excess of certain types of atrophy and congenital abnormalities. They also found that participants with Down’s Syndrome had a smaller cerebellar volume and lateral ventricular enlargement compared to the control group.

They also found a different pattern of brain anomalies in those individuals with dementia compared to those without. Moreover, the pattern of anomalies found in the brains of participants with dementia was similar to that reported in other studies in individuals without Down’s Syndrome but with a diagnosis of dementia (e.g. Pearlson et al. 1990).

Despite these promising results the number of people investigated with both Down’s Syndrome and a confirmed diagnosis of dementia were small. Questions could also be raised about the unequal size of the control group and how closely matched both groups were in terms of age, sex and ethnicity. Again, as in the Prasher et al. (1996) study, this was not a longitudinal study. It is therefore difficult to make any comments on the neuropathological correlates of Alzheimer’s disease over time. As individuals with Down’s Syndrome show a range of developmental neuropathologies which vary in both type and severity a one off MRI scan would perhaps have difficulties differentiating anomalies specific to Alzheimer’s disease from those more general to Down’s Syndrome, particularly in the early stages of a dementing process.

It would appear then, that although the use of neuro-imaging techniques can be a useful tool in the diagnosis of Alzheimer’s disease in Down’s Syndrome, both in terms of differential diagnosis and diagnosis of dementia, not enough is currently known about brain neuropathology in either Alzheimer’s disease or Down’s Syndrome for them to be used as a definitive test for Alzheimer’s disease in people with Down’s Syndrome. At best they can be seen as a useful adjunct to other methods of diagnosis.
2.4. The Use and Efficacy of Psychometric Assessment in the Diagnosis of Alzheimer’s Disease in People with Down’s Syndrome

One of the most generally accepted ways of assessing an individual for evidence of a dementing process is to use a well standardised psychometric assessment. This is usually carried out at the first signs of cognitive deterioration in order to provide a baseline measure for comparison over time. The rate and pattern of deterioration as measured by the repeat administrations of the assessment tool allows a diagnosis of Alzheimer’s disease to be made. However, few assessment tools used in the general population are appropriate for use with a learning disability population either because they produce floor effects or are not standardised on a learning disability or Down’s Syndrome population (Witts & Elders 1998). Most assessment measures are also heavily reliant on verbal communication skills and therefore would only be suitable for people with a mild or moderate learning disability, and only then in the early stages of a dementing process (Dalton & Crapper-McLachlan, 1986). In recent years a number of studies have been carried out examining the use of neuropsychological assessments- traditionally used within the general population - with a learning disability population e.g. the ‘Severe Impairment Battery’ (Witts & Elders, 1998) and the ‘Cambridge Cognitive Examination’ (Hon, Huppert, Holland & Watson, 1999). To date though, only two assessment tools have been devised specifically to aid diagnosis of dementia in people with learning disabilities: ‘The Dementia Questionnaire for Persons with Mental Retardation’ (Evenhuis, 1990) and ‘The Dementia Scale for Down’s Syndrome’ (Gedye, 1995).

2.4.1. The Dementia Questionnaire for Persons with Mental Retardation (DMR)

The DMR was developed as a diagnostic screening instrument and as a way of promoting the standardised observation and recording of essential data needed for a diagnosis of dementia (Evenhuis 1992). The DMR is completed by a carer who knows the individual with learning disabilities well. The questionnaire consists of 50 items with a simple linear scoring system that yields a sum of cognitive scores (i.e. short-term memory, long-term memory, and spatial and temporal orientation) and a sum of social scores (i.e. speech, practical skills, mood, activity and interest, and behavioural disturbance). The
higher the scores on the sub-scales the more severe the deterioration is. A longitudinal study of 139 patients in a long stay hospital carried out by Evenhuis (1992) showed that changes of a certain magnitude in cognitive scores and social scores over a one year period were indicative of a dementing process. Changes in cognitive scores were found to have a higher sensitivity to early signs of dementia than social scores. In clinical terms this may lead to better early detection of dementia in people with Down’s Syndrome.

Although the initial aim of the DMR was to measure deterioration over time and therefore allow a diagnosis of dementia to be made, Evenhuis (1996) has also investigated its use as a one off screening assessment for dementia. In this study, unlike the initial study, Evenhuis also included 45 people with Down’s Syndrome who at the start of the study exhibited no signs of dementia. This study confirmed Evenhuis’s early findings that changes in the sum of cognitive scores (SCS) over time were the most specific criterion for a diagnosis of dementia.

In terms of an absolute cut off score for dementia, Evenhuis found that results were comparable with a diagnosis based on SCS changes over time. However, she warns against using a one off DMR score to diagnose dementia. One reason given for this is the need for pre-morbid information on level of functioning, both functional and intellectual. As there are many ways of assessing both the functional skills and intellectual abilities of people with learning disabilities, information on pre-morbid abilities may not be particularly reliable or consistent between one individual and another. Another concern was the high rate of false positive scores within the Down’s Syndrome group. It was found that in 13 of the 44 individuals with Down’s Syndrome who met DMR criteria for dementia their symptoms were accounted for by conditions other than dementia e.g. hearing loss, visual loss, hypothyroidism and depression. For this reason Evenhuis states that the DMR can never be as sensitive as a skilful psychiatric examination and should not be used in place of careful clinical examination.

The DMR however, has several strengths. Firstly it has good face validity when compared with ICD-10 criteria for Alzheimer’s disease. Separate sub-scales for
‘cognitive’ and ‘social’ items also allow for easier detection of dementia. As stated above, the first indicators of dementia in those with Down’s Syndrome may be behavioural rather than cognitive - behavioural disturbance being included in the ‘social’ subscale. The DMR has been standardised using a longitudinal design, taking place over more than seven years. This has allowed the progression of dementia in people with learning disabilities to be studied over time and has tested the questionnaire’s sensitivity to early detection of dementia. As the questionnaire does not rely on the verbal abilities of the individual being assessed but rather on carer report it can be used with people with varying degrees of learning disability. Indeed score changes needed for a diagnosis of dementia are provided not only for people with a mild learning disability but also for those with a moderate and severe learning disability - although they perhaps become less sensitive at the lower end of the learning disability spectrum. The questionnaire can also be completed by carers who need little or no training in its use and is therefore cost effective for services. Further evaluation of the scale has also included people with Down’s Syndrome, therefore increasing its validity with this population.

However, there are a number of drawbacks to the DMR. Although the questionnaire is to be completed by carers who know the client well, the nature of learning disability services means that the questionnaire may not necessarily be completed by the same carer on repeated administrations. This could seriously affect the reliability of the measure as different care staff may not agree on the nature or severity of the individual’s difficulties. Also at the current time, there continues to be the need for repeated administration of the questionnaire before a diagnosis can be made. This means that diagnosis of dementia and possible treatments are delayed. The questionnaire can also give false positive results meaning that it still needs to be used in conjunction with other methods of diagnosis such as psychiatric assessment and medical investigation.

2.4.2. The Dementia Scale for Down Syndrome (DSDS)

The DSDS (Gedye, 1995), like the DMR, is a carer report assessment but, unlike the DMR, it has been specifically devised to aid diagnosis of dementia in people with Down’s Syndrome. It consists of 60 questions divided up equally over three categories
indicating: ‘early’, ‘middle’ and ‘late’ stages of dementia. To minimise response bias the questionnaire is meant to be completed by two carers who know the individual well and should be administered by a chartered psychologist. The interview begins with questions about symptoms of early stage dementia and behaviours are rated as being ‘absent’, ‘present’, ‘not applicable’ or ‘typical of that individual’. This allows for newly developed behaviours to be differentiated from long standing behaviours displayed by the individual. If a threshold score is not met for questions under the ‘early’ stages of dementia the questionnaire is discontinued. The same also holds for ‘middle stages’. The DSDS also allows for a differential diagnosis of Alzheimer’s disease with depression, hypothyroidism, and hearing and visual impairment.

There are few reports of the DSDS in the literature. One study carried out by Deb and Braganza (1999) has investigated the clinical utility of the DSDS as well as comparing it to the DMR. It was found that the DSDS showed good specificity and sensitivity when compared with a clinician’s diagnosis of Alzheimer’s disease. Moreover, scores on the DSDS also had a good positive correlation (Pearson’s rho = .868) with scores on the DMR. This suggests good criterion validity for both the DSDS and the DMR.

The DSDS is a welcome addition to existing assessment tools for dementia in people with Down’s syndrome. It has several strengths when compared with other assessment tools. Firstly it has been specifically devised and standardised on a Down’s Syndrome population. It requires two raters to complete the questionnaire and therefore reduces the likelihood of response bias. It also distinguishes pre-existing behaviours from newly displayed behaviours perhaps linked to dementia. This means that the questionnaire is less likely to show floor effects as established behaviours are not scored. As there are clear cut off points it also allows for the specific stage of dementia to be diagnosed. This means that the DSDS can be used as a one off screening instrument. Importantly with this client group it also allows for differential diagnoses to be made.

However, as the DSDS is a relatively recent addition to the dementia test battery very few studies have been conducted examining its clinical effectiveness and utility. The requirement that it should be completed by a chartered psychologist also has cost and
The ‘Severe Impairment Battery’ was developed by Saxton, McGonigle, Swihart and Boller (1993) in order to assess the cognitive skills of severely dementing clients. Test items are based upon the specific behavioural and cognitive deficits associated with dementia. The battery has subsections for attention, orientation, language, memory, visuoperception, construction, praxis and social interaction. Items are based on simple one step commands and are used alongside gestural cues in order to counteract the severe comprehension difficulties that may be present in the client. It is suggested that a score of less than 63 out of a possible 100 indicates very severe impairment. With repeated administration it is possible to plot the client’s cognitive deterioration over time.

To date, only one study has looked at the use of the SIB with people with Down’s Syndrome. Witts and Elders (1998) examined both the utility of the SIB with a Down’s Syndrome population and its test-retest reliability for this population.

Thirty three individuals with Down’s Syndrome but no clinical signs of dementia were included in the study and were assessed using both the SIB and the ‘Vineland Adaptive Behaviour Scales’ (ABS), (Sparrow, Balla & Cicchetti, 1984) - a well-established test within learning disability services with good psychometric properties. The tests were administered twice at 30-day intervals. A significant correlation (Spearman’s rho = .68) was found between ABS age equivalent scores and SIB scores. Test - retest reliability of the SIB was also high (Spearman’s rho = .89).

Although the test appears to have good test-re-test reliability and criterion validity (when compared to the Vineland ABS), there are a number of apparent difficulties when it comes to using the SIB with a Down’s Syndrome population. The test may only be suitable for a narrow range of individuals with Down’s Syndrome i.e. those who are able to read, as certain subtests require the individual to read aloud a word from a card. At present there is no normative data for a learning disability/Down’s Syndrome population.
included in the test. This means that the cut off point of 63 for severe impairment may not be accurate for a Down’s Syndrome population. Indeed, Witts and Elders found that several individuals had a score of less than 63 but presented with no clinical signs of dementia. As people with learning disabilities all have different pre-morbid abilities there is little use in only administering the SIB once. Repeated administration over time is again the only reliable way of detecting deterioration in cognitive skills and therefore of diagnosing a dementing process.

However, unlike the DMR, which relies upon carer information, the SIB is carried out directly with the individual, therefore increasing its reliability over time. With further research and normative data the SIB may become a very useful tool in the diagnosis of dementia in people with Down’s Syndrome.

2.4.4. The Cambridge Cognitive Examination (CAMCOG)

The Cambridge Cognitive Examination was initially designed for the general elderly population to assess cognitive impairments characteristic of dementia. It is part of the Cambridge Examination for Mental Disorders of the Elderly (CAMDEX), (Huppert, Brayne, Gill, Paykel & Beardsall, 1995). CAMCOG items are divided into several broad areas of cognitive functioning i.e. orientation, language, memory, attention and calculation, praxis, abstract thinking and perception. Some of the broad areas are also subdivided i.e. language is divided into comprehension and expression and memory into remote and recent memory and incidental and intentional learning. It has been shown in the general elderly population that the CAMCOG total score and scores on each of the subscales differentiate significantly between healthy individuals and those with mild dementia (Huppert et al., 1996).

The CAMCOG, with slight modification, has been tested on a Down’s Syndrome population with promising results (Hon, Huppert, Holland & Watson, 1999). Hon et al. investigated the use of the CAMCOG with 74 individuals with Down’s Syndrome with varying degrees of learning disability, both with and without a diagnosis of Alzheimer’s disease. They did this in order to test its use as a diagnostic tool for dementia and to
investigate whether there is a significant difference in cognitive performance between younger and older adults with Down’s Syndrome. Twenty one of the 74 participants had severe or profound learning disabilities, severe visual and hearing impairments or a pre-existing diagnosis of Alzheimer’s disease.

It was found that for the 21 participants mentioned above there was a marked floor effect. This indicates that the CAMCOG is only useful in the assessment of people with mild to moderate learning disability and those at the early stages of a dementing process. Total CAMCOG scores and all subscale scores except those for ‘attention/calculation’ were found to be strongly related to age, with participants over the age of 45 performing worse than younger participants. This finding supports the findings of other studies (see Oliver et al., 1998) that people with Down’s Syndrome over the age of 40 are affected by general age-related cognitive decline.

The CAMCOG like the DMR and SIB has good face validity when compared with ICD-10 criteria for dementia. Unlike other assessment tools the CAMCOG has been tested specifically on a Down’s Syndrome population and has been shown to be effective at detecting age related cognitive decline in those over 40 years of age. Unfortunately in common with other assessment tools, CAMCOG is of limited use with individuals who have severe or profound learning disabilities. Although the CAMCOG allows cognitive decline to be measured in those without a diagnosis of dementia it is unclear from Hon et al.’s. study how the scores for individuals with dementia can be differentiated from those with general age related cognitive decline. No norms or cut off points are provided which are indicative of a dementing process. As with other neuropsychological assessments for dementia the CAMCOG’s real strength is in providing an assessment tool which can be repeated over time, allowing both the speed and nature of cognitive decline to be measured.

To date, only two psychometric assessment tools, the DMR and the DSDS, have been devised for and standardised on a learning disability population. Some of the existing assessment tools used within the general population for diagnosing dementia have shown promising results when used with a Down’s Syndrome population. However, there
continues to be a lack of normative data for this client group. All of the assessment tools discussed above (with the exception of the DSDS) need to be repeated over time in order to assist in the diagnosis of dementia and none are effective enough to be used in isolation. Despite this, psychometric assessment has a crucial role to play in the diagnosis of Alzheimer’s disease in people with Down’s Syndrome.

2.5. A Multi-Modal Approach to the Diagnosis of Alzheimer’s Disease in People with Down’s Syndrome

It is clear that at the current time the diagnosis of dementia in people with Down’s Syndrome can not and should not rely on information from one particular type of assessment. For an accurate diagnosis to be made information is needed from a variety of sources and covering a number of different domains i.e. medical, psychiatric, neurological and neuropsychological.

The working group for the Establishment of Criteria for the Diagnosis of Dementia in Individuals with Intellectual Disability (Aylward, Burt, Thorpe, Lai & Dalton, 1997) have proposed a set of recommended procedures for the diagnosis of dementia in individuals with intellectual disability (see Appendix Three). These are linked closely to ICD-10 criteria for dementia and recommend assessment in the areas of memory, cognitive abilities, awareness of the environment, and emotional control/motivation or change in social behaviour. To carry out such an assessment requires a combination of clinical evaluation and the administration of a number of standardised assessment tools.

2.6. Conclusion

Relatively little is known about the nature of Alzheimer’s disease in people with Down’s Syndrome. Although all people with Down’s Syndrome over the age of 35 have the neuropathological markers of Alzheimer’s disease only about 36 per cent go on to develop clinical symptoms of dementia. For mental health professionals there is a danger of pre-maturely diagnosing cognitive deterioration in people with Down’s Syndrome as Alzheimer’s disease. As yet there is no simple or straightforward way of making such a
diagnosis. Although certain neuro-imaging techniques have been successful in identifying anomalies in the brains of individuals with Down’s Syndrome and dementia, not enough is known about pre-morbid anomalies related to intellectual impairment to make results from these techniques categorical. Advances in psychometric assessment mean that there is now a range of useful and effective assessment tools for diagnosing dementia in people with learning disabilities. However, the majority of these need to be used longitudinally and information is required on pre-morbid levels of functioning. There also remains the possibility of false positive results on these assessments related to the issue of differential diagnosis.

At the present time it is only through following a thorough and detailed, multidisciplinary assessment procedure as advocated above by the working group for the Establishment of Criteria for the Diagnosis of Dementia in Individuals with Intellectual Disability that an accurate diagnosis of Alzheimer’s disease can be made in people with Down’s Syndrome. In practice this means that health care professionals need to work together to arrive at a diagnosis of Alzheimer’s disease. A thorough medical examination, possibly involving neuro-imaging techniques is required to rule out other possible organic causes of cognitive decline such as hypothyroidism or cerebrovascular accident. Psychiatric assessment is required to rule out psychopathology such as depression or psychosis. Once medical and psychiatric conditions other than dementia have been eliminated there is a need for a thorough assessment of the individual’s current abilities and difficulties. This should include clinical interviews with the individual and their carers to trace the course of the individual’s difficulties over time. Clinical psychologists will then need to conduct neuropsychological assessment, which will need to be repeated at regular intervals in order to investigate the pattern and rate of cognitive decline. It is only by following such stringent procedures that a clear diagnosis of dementia and in particular dementia of the Alzheimer type can be made. If these procedures are not followed it may lead to people with Down’s Syndrome being misdiagnosed and therefore being denied treatment for curable illnesses.
2.7. References


prospective study of age related cognitive change in adults with Down’s syndrome. Psychological Medicine, 28, 1365-1377.


Appendix One

DSM IV Criteria for Dementia of the Alzheimer’s Type.

A. The development of multiple cognitive deficits manifested by both

1. Memory impairment (impaired ability to learn new information or to recall previously learned information).

2. One (or more) of the following cognitive disturbances:
   a. Aphasia (language disturbance)
   b. Apraxia (impaired ability to carry out motor activities despite intact motor function)
   c. Agnosia (failure to recognize or identify objects despite intact sensory function)
   d. Disturbance in executive functioning (i.e. planning, organizing, sequencing, abstracting)

B. The cognitive deficits in Criteria A1 and A2 each cause significant impairment in social or occupational functioning and represent a significant decline from a previous level of functioning.

C. The course is characterized by gradual onset and continuing cognitive decline.

D. The cognitive deficits in Criteria A1 and A2 are not due to any of the following:

1. Other central nervous system conditions that cause progressive deficits in memory and cognition (e.g. cerebrovascular disease, Parkinson’s disease, Huntington’s disease, subdural haematoma, normal pressure hydrocephalus, brain tumour)

2. Systemic conditions that are known to cause dementia (e.g. hypothyroidism, vitamin B12 or folic acid deficiency, niacin deficiency, hypercalcemia, neurosyphilis, HIV infection)

3. Substance-induced conditions

E. The deficits do not occur exclusively during the course of a delirium.

F. The disturbance is not better accounted for by another Axis I disorder (e.g. Major Depressive disorder Schizophrenia).
Appendix Two  ICD-10 criteria for dementia and Alzheimer’s disease.

1. **Decline in memory**
   Most evident in the learning of new information, although the recall of previously learned information may also be affected in more severe cases. The impairment applied to both verbal and nonverbal material.

2. **Decline in other cognitive abilities**
   Characterized by deterioration in judgement and thinking such as planning and organizing and in the general processing of information. Deterioration from a previously higher level of performance should be established.

3. **Awareness of the environment**
   Absence of clouding of consciousness for a period of time sufficiently long to allow the unequivocal demonstration of decline in memory and other cognitive functions.

4. **Decline in emotional control or motivation, or change in social behaviour**
   Changes are manifested in at least one of the following: (1) emotional lability; (2) irritability; (3) apathy; (4) coarsening of social behaviour.

5. **Duration**
   Decline in memory and other cognitive functions must be present for at least 6 months.

   1. All criteria for dementia are met
   2. Exclusionary criteria:
      No evidence from the history, physical examination or special investigations for any other possible cause of dementia e.g. a systemic disorder or alcohol or drug abuse.
   3. Onset and progression:
      For a diagnosis of AD, (Alzheimer’s disease), there must be evidence of gradual onset and continuing cognitive decline.
### Appendix Three  
ICD-10 criteria for dementia and Alzheimer disease & recommended evaluation procedures.

<table>
<thead>
<tr>
<th>1. Decline in memory</th>
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<tbody>
<tr>
<td><strong>Dementia scales:</strong></td>
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<tr>
<td>Dementia Questionnaire for Mentally Retarded Persons (Evenhuis et al., 1990),</td>
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<tr>
<td>Dementia Scale for Down Syndrome (Gedye, 1995)</td>
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<tr>
<td><strong>Mental status exam:</strong></td>
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<tr>
<td>Down Syndrome Mental status Examination (Haxby 1989)</td>
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<tr>
<td>Test for Impairment (Albert &amp; Cohen, 1992)</td>
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<tr>
<td><strong>Neuropsychological tests:</strong> Tests of verbal and nonverbal memory, &amp; immediate and delayed memory.</td>
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<th>2. Decline in other cognitive abilities</th>
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<td><strong>Dementia scales:</strong> See above</td>
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<tr>
<td><strong>Mental status exam:</strong> See above</td>
</tr>
<tr>
<td><strong>Adaptive behaviour scales:</strong> Scales of Independent Behaviour (Bruininks et al., 1985)</td>
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<tr>
<td>Vineland Adaptive Behaviour Scales (Sparrow et al. 1984)</td>
</tr>
<tr>
<td>Disability Assessment Scale (Holmes et al. 1982)</td>
</tr>
<tr>
<td><strong>Neuropsychological tests:</strong> Tests of expressive and receptive language, fine motor skills, visual-spatial functioning.</td>
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<th>3. Awareness of the environment</th>
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<tr>
<td><strong>Clinical evaluation:</strong> General, physical, neurological &amp; psychiatric examination</td>
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<tr>
<td>(The diagnosis of dementia should be deferred during superimposed delirium).</td>
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<th>4. Decline in emotional control or motivation, or change in social behaviour</th>
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<tr>
<td><strong>Dementia scales:</strong> See above</td>
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</tbody>
</table>
Maladaptive problem behavior scales:
- Aberrant Behaviour Checklist (Aman et al., 1985)
- Maladaptive Sections of Adaptive Behaviour Scales

Psychopathology scales:
- Reiss Screen for Maladaptive Behavior (Reiss, 1987)
- Diagnostic Assessment for the Severely Handicapped (Matson, 1994).
- Psychiatric Assessment Schedule for Adults with a Developmental Disability (HARC, 1994)

History/ Caregiver interview:
- Dementia Scale for Down's syndrome (Gedye 1995)

5. Duration

1. All criteria for dementia are met
   
   Clinical Evaluation

2. Exclusionary criteria:

   Behavioural/psychiatric evaluation, laboratory studies (as needed)
   Adapated vision examinations
   Adopted hearing examinations
   Acoustic-immittance, auditory evoked potentials

3. Onset and progression:

   Hachinski Scale (Hachinski 1990) (Assessment of multi-infarct dementia).
   Longitudinal administration of dementia scales, mental status exams and/or neuropsychological tests.
   Longitudinal administration of behavioural and adaptive measures.
CRITICAL REVIEW TWO

What Evidence is there to Suggest that Psychoanalytic Psychotherapy is an Effective Form of Treatment for People with Learning Disabilities?
3.0. Introduction

"Any discussion of the value and limitations of individual psychotherapy with the feebleminded\(^1\) must be evaluated in light of the fact that there has been practically no systematic research in this area".\(^2\) (Sarason, 1951, p.803)

Since the time of Sarason’s comments, and in particular within the last twenty years, there has been a growing interest in the application of psychoanalytic\(^2\) or psychodynamic psychotherapy to the treatment of people with learning disabilities. Many professionals including psychotherapists, psychiatrists, drama-therapists, art therapists, music therapists, social workers, counselling psychologists and clinical psychologists would state that their work with learning-disabled individuals is informed and guided by psychoanalytic theory and practice. At the Tavistock Clinic\(^3\) in London, interest in working psychoanalytically with people with learning disabilities began in 1979, based on the clinical experiences of Neville Symington; and since 1995 there has been a specific psychotherapy service at the Tavistock for children, adolescents and adults with learning disabilities (Hernadez-Halton et al., 2000). Indeed a survey conducted by Nagel & Leiper (1999) found that as many as 41 per cent of psychologists working in the UK with clients with learning disabilities would consider themselves to have some competency in working psychoanalytically with this client group.

Given the increased prevalence of emotional disorders in people with learning disabilities (Nezu & Nezu, 1992; Reiss & Tren, 1984) it is reassuring to see a wider range of treatment options being made available to this often neglected client group. However, in the current NHS climate of evidence-based practice (see Government documents Signposts for Success, 1998; & Valuing People, 2001) and resource shortages, what evidence is there to indicate that psychoanalytic psychotherapy (an

\(^1\) This was a diagnostic term used to refer to people with learning disabilities

\(^2\) The terms psychodynamic psychotherapy and psychoanalytic psychotherapy will be taken to mean the same thing in the context of this review.

\(^3\) The Tavistock Clinic is an international centre of excellence in the teaching and practice of psychoanalytic psychotherapy.
often intensive and long-term endeavour) is an effective and lasting form of treatment for people with learning disabilities?

As early as 1951, Sarason was calling for more systematic research into the use of psychoanalytic psychotherapy for people with learning disabilities. Despite the growing interest in this method of working there remains a dearth of literature exploring the efficacy of psychoanalytic psychotherapy for this client group. Nearly 50 years later Hollins and Sinason (2000) continue to call for more research into the outcome of psychoanalytic psychotherapy for people with learning disabilities.

The aim of this review is to examine the limited number of papers available which detail outcome or evaluation of psychoanalytic psychotherapy for individuals with learning disabilities. Earlier papers tend to be in case study format, mentioning outcome in purely qualitative and anecdotal terms. Within the more recent literature there are a number of papers which take a systematic, research based approach to outcome and evaluation. Papers pertaining to both individual and group psychotherapy will be reviewed.

3.1. Considerations for effective outcome research

Given the number of calls in the literature for more systematic research into the effectiveness of psychoanalytic psychotherapy for people with learning disabilities, it is important to be clear from the outset about the criteria on which such studies should be judged. Nezu & Nezu (1994) argue that whenever possible group designs with random assignment and adequate control groups should be the standard. Such randomised control trials (RCTs), although traditionally held to be the gold standard of treatment efficacy research, were not employed by any of the studies reviewed in this paper. This is probably due to the resource implications (e.g. financial issues, number of participants required, number of clinicians needed) of employing such a rigorous research methodology. This is a particularly pertinent issue for the studies reviewed in this paper which were predominantly carried out by clinicians as part of their routine work.
Blampied (2001), although not dismissing RCTs entirely, advocates the use of single-case designs for measuring effectiveness of psychotherapies. Nezu & Nezu (1994) also support the use of well-designed case studies when RCTs are not feasible. Within single-case studies the therapeutic results of a specific treatment are compared with results obtained under different conditions such as pre-treatment baseline, post-treatment follow-up, no treatment, or an alternative treatment. Blampied argues that such an approach allows clinical innovations to be fully investigated (at the level of the individual), without large numbers of individuals being exposed to unproven treatments. In his view, such studies should be the precursor to RCTs. A number of studies in this review have adopted a single-case design.

Within any well-designed research study examining treatment outcome, the inclusion of a control group is crucial (Nezu & Nezu, 1994). The use of a control group, particularly one that is matched on a range of dimensions (e.g. age, sex, intellectual ability), adds considerable weight to the validity of a study’s findings. However, certain ethical considerations need to be taken into account when employing a control group. One objection to their use is that treatment is being withheld from this group and they may suffer as a consequence. Although not utilized by many of the studies being reviewed, control or comparison groups were employed by a small number and in such a way as not to deprive individuals of the treatment they needed.

Another criticism levied at studies carried out in this area is their over-reliance on clinical impression or process issues as a measure of outcome (Gravestock & McGauley, 1994; Nezu & Nezu, 1994). Rather than relying on anecdotal evidence or subjective opinion there is a need for objective, standardised and multi-dimensional assessment and outcome measures. These should elicit the views of family or carers as well as the client, and attempt to measure observable changes in behaviour e.g. decrease in frequency of challenging behaviours; increase in adaptive behaviours. Positive effects should also be shown to last over time, meaning that studies should have an adequate follow-up period. In practice though, there is often a lack of validated and reliable assessment measures suitable for use with people with learning disabilities. Faced with the lack of appropriate outcome measures, Beail (1995)
advocates taking measures routinely used in adult mental health and modifying them for use with people with learning disabilities.

Although there is clearly a need to re-focus on objective outcome measures, Pfadt (1991) warns against ignoring process issues altogether when addressing the issue of outcome. He argues that exploration of process issues (termed process research) can establish whether the preconditions necessary for therapeutic change were operationalized within the therapy. If so, this can add support to the case that any changes in clients' behaviour are attributable to the therapy rather than extraneous factors.

So, with the above criteria in mind studies discussing the use of psychoanalytic psychotherapy, both in terms of individual and group therapy, will be reviewed.

3.2. Outcome of individual psychoanalytic psychotherapy

Although case studies of psychotherapy with people with learning disabilities began to appear in the American literature in the late 1940s and early 1950s (see Cotzin, 1948; Fisher & Wolfson, 1952; Thorne, 1948), the first published case report in the UK did not appear until over thirty years later. This was Neville Symington's (1981) account of once weekly psychotherapy for a 33-year-old man with learning disabilities, which gave rise to the specialist psychotherapy service for people with learning disabilities at the Tavistock Clinic. In the case study Symington gives a detailed account of the therapy process which took place over the course of two years until terminated by the client. In terms of outcome, Symington honestly admits that he “did not know whether the treatment was a success or a failure” (p.187). Although initially referred to therapy by day centre staff because of “violent tantrums” no baseline measurement of the frequency or duration of these incidents was taken and no reference is made to them following termination of therapy. Symington did however, carry out follow up interviews with both the client's family and members of staff from the day centre. This indicated a number of changes in the client’s behaviour, the most notable being his increased capacity to look after himself and to conduct a conversation – something that would have been impossible prior to therapy; and a reduction in anxiety. It is
unclear how, apart from observer account, reduction in anxiety was measured. On the whole, Symington overlooks the issue of outcome in this study. He does however give a detailed and instructive account of the therapy which undoubtedly encouraged others to take people with learning disabilities into psychoanalytic psychotherapy.

Following Symington’s seminal work, a number of other case studies began to appear in the literature outlining psychoanalytic or psychodynamic psychotherapy for people with learning disabilities. However, for the most part these were concerned with the application of psychotherapy and process issues rather than on the evaluation of outcome (Beail, 1995). Although not addressing therapy outcome in any rigorous, systematic or formal way, a number of studies have included anecdotal accounts of treatment outcome.

Balbemie (1985a, 1985b) wrote two case studies of children with learning disabilities whom he saw for weekly psychotherapy. The first was an account of therapy with a 13½ year old boy who engaged in head-banging, and who was referred for therapy by his school. In terms of symptom reduction, no information is provided on the frequency or severity of head-banging at the outset of therapy. Balbemie does state however, that after about two years in therapy, and following a particularly salient interpretation, the client ceased to engage in head-banging. Reference is also made to changes that took place a few months into the therapy. Balbemie notes that his client was in trouble less of the time and was able to join a youth club. No attempt is made in the case study to quantify terms such as ‘less of the time’.

In the second case study Balbemie gives an account of an 11-year-old boy referred to therapy for ‘continual aggression’. Again, although no attempt is made to quantify ‘continual’, Balbemie does state that the boy would spend all of his unsupervised time picking fights. When therapy terminated, after one year, Balbemie states that his client had ceased to be aggressive, no-longer picked fights, and was viewed as being a different boy, both at school and at home. Again, a detailed account of process issues is given in both of these case studies highlighting the fact that children with learning disabilities can participate in and make use of psychoanalytic therapy. It is less clear though, how effective therapy was in bringing about lasting change.
Frankish (1989), although still very much within a case study format, provides a more systematic account of psychotherapy with seven learning disabled clients. She states that she did this in response to Stavrakaki & Klein's (1986) call for further evaluation and more systematic studies in this area. Within this study, Frankish gives a clear account of the theoretical model guiding her practice as well as short descriptions of the therapy with each of her clients. The clients were aged between 5 and 24 years and length of treatment varied between 9 months and 2½ years. Some of the clients were still in treatment when the study was written and so comments on outcome do not necessarily refer to outcome at completion of therapy. In this study outcome has been measured in terms of changes in observable behaviours. These are presented in the format of qualitative statements with no attempt being made to quantify behaviours, either pre-or post-therapy. The statements on outcome indicate that all clients showed a decrease in their presenting problems although in only one case was the presenting problem completely eliminated. Again, no information is provided on follow-up making it impossible to judge the efficacy of the treatment over time.

The first account in the literature of an attempt to measure psychotherapy outcome in a more objective and standardised way comes from Beail (1994). He gives an account of once weekly psychoanalytic psychotherapy for a man who had been ritually abused. Although still written within a case study format, Beail uses an adapted and simplified version of the 'Symptom Checklist-90' (SCL-90R) (Derogatis, 1983), to give an objective measure of outcome. The SCL-90R is a tool often used in psychotherapy outcome studies in adult mental health to monitor changes in symptomatology over time (Lambert & Hill, 1994), and as such was deemed to be suitable, following modification, for use in an outcome study with people with learning disabilities. It yields scores for nine symptom areas as well as a general severity index score. The SCL-90R was carried out by a research assistant every eight sessions and the therapist was not informed of the scores until the end of therapy. At the outset of therapy the client had a SCL-90R score of 70. After eight sessions there was a slight drop in score but this remained stable until after the 32nd session. By the 40th session the score had reduced to 37 and by the end of therapy (session 48) to 32. Although this appears to be a good indication of symptom reduction, no statistical
analysis was carried out on the scores in order to give a measure of significance. A lack of information on the process of therapy also makes it difficult (in terms of process research) to assess if changes in symptom score were related to treatment process. As in previous studies the issue of follow-up was not addressed. However, this is the first account in the literature of a study which has attempted to measure outcome in a more objective manner by adopting a single-case methodology. Beail developed this idea further and applied a similar, albeit more rigorous, methodology to the evaluation of a psychodynamic psychotherapy service for adults with learning disabilities (Beail & Warden, 1996).

In this study Beail & Warden (1996) use the SCL-90R (as discussed above) and the ‘Rosenberg Self-Esteem Scale’ (1965) to measure the effectiveness of psychodynamic psychotherapy for 10 people with learning disabilities. The clients ranged in age from 18 to 49 years and the length of therapy varied from 5 to 48 sessions (mean = 18). As above, the measures were administered independently of the therapy by an assistant psychologist and were carried out at intake, after every eight sessions, at termination of therapy and at three-month follow-up. This is the first time that follow-up data has been included in the literature. Results from the SCL-90R and the Rosenberg Self-Esteem Inventory indicated positive changes in scores from intake to follow-up. The differences in scores were subjected to statistical analysis using a repeated measures analysis of variance and were found to be statistically significant at the 0.05 level of probability. General Severity Index scores from the SCL-90R were compared to normative data for a ‘non-patient’ population and indicated a decrease from being above the criteria for ‘caseness’ at intake to below at termination of therapy and follow-up. This is also the first time that gains made in therapy have been shown to continue beyond termination of therapy. Despite the positive findings of this study and the support it adds to the now growing literature on treatment efficacy, a number of methodological issues need to be considered. Firstly no control or comparison group is included in the study. Inclusion of a control group would add support to the claim that changes in scores were brought about through the therapy process rather than through extraneous factors. By modifying the language and structure used in standardised measures to make them accessible to a learning disability population the psychometric properties of these measures may well have been altered. This would
make any comparisons with normative data from a non-patient sample invalid. Re-standardization of suitable outcome measures such as the SCL-90R to include normative data on a ‘non-patient’ learning-disabled population needs to be considered.

A three year longitudinal study carried out by Bichard, Sinason & Usiskin (1996) managed to address the concerns raised by Beail & Warden’s study by employing a control or ‘contrast’ group and by using a range of cognitive tests (i.e. either Columbia Mental Maturity Scale, British Picture Vocabulary Scale, WAIS-R or Stanford Binet) and a projective test (i.e. The Draw a Person Test - DAP) which did not require modification for use with a learning-disabled population. The DAP test has been shown to be a sensitive measure of psychological adjustment and therapeutic change (Yama, 1990). The stated aims of this study were to ascertain which clients showed improvement after one, two and three years of psychotherapy (as measured by changes in the DAP scores); whether this could have been predicted from initial assessment; and whether clients showed marked variations in rate of improvement as measured by the DAP score. The clients, 16 adults referred to an outpatient psychotherapy clinic, were assessed at the beginning of the study, before entering therapy and each year until therapy terminated. Of the 16 original participants five left therapy within the first year and were therefore not included in the longitudinal study; three left after one year and their results are included in the first analysis; and the remaining eight were seen in weekly psychoanalytic psychotherapy for 2-3 years. The control group consisted of eight people who had been referred for psychotherapy but could not be treated due a lack of therapeutic vacancies. After the first year of therapy it was found that all but two of those in treatment showed improved scores whereas only one of the contrast group showed improvement in scores. After two years in therapy seven of the eight remaining clients in therapy showed improved scores whilst only one of the contrast group had increased scores. Of the four clients who remained in therapy for three years all had increased DAP scores compared with those at the outset of therapy. Statistical analysis indicated that differences in scores were highly significant. In relation to the initial aims of the study it was found that neither IQ score or initial DAP score could predict which clients will demonstrate the greatest improvement in therapy and that there is little correlation between initial IQ score and changes in DAP score over time. Within this study, Bichard et al. have effectively
measured outcome of psychotherapy by adopting a rigorous research methodology. However, little reference is made in the study to therapeutic process and no data is included on long-term follow-up.

The importance of outcome studies addressing long-term follow-up cannot be underestimated. For any treatment to be deemed effective the gains made during therapy in terms of symptom reduction or decrease in challenging behaviours need to be sustained over time. Beail and Warden (1996) have already demonstrated that therapy gains were maintained by the clients in their study at three-month follow-up. In a further study Beail (1998) discusses outcome of therapy in relation to a six-month follow-up period. The basis of this study was individual psychotherapy with 20 learning-disabled men who had been routinely referred over a three-year period to a district psychology service, 12 because of behaviour problems (e.g. aggression) and 8 because of offending behaviour. Length of therapy varied from 3 months to 43 months, with 9 clients being in therapy for less than 6 months. Effectiveness of treatment was based on the frequency of behaviour problems or number of incidents of re-offending. Both of these measures were made through the use of carer interview and monitoring diaries. Assessments were carried out at outset of treatment, at termination of treatment and at six-month follow-up. Although this study did not employ a formal control group, four men who were initially referred for therapy but who did not complete treatment were also followed up. It was found that for eleven of the men referred for behaviour problems the problems were eliminated by the end of therapy. This was also maintained at six-month follow-up. For one client the behaviour was not eliminated completely but was reduced from occurring daily to once weekly. Again this was maintained at six-month follow-up. No further offending behaviour was observed in the offender group either at termination of therapy or at six-month follow-up. The four participants who did not complete treatment showed the same level of behaviour problems when followed-up as they did at intake. Information is included in this study on process issues as well as outcome and demonstrates that even within a short space of time (i.e. six months) psychodynamic psychotherapy can be an effective and lasting form of treatment for challenging behaviours.
Studies reporting individual psychotherapy for people with learning disabilities have developed over time from case studies illustrating the application and process of psychoanalytic psychotherapy with a learning-disabled population to studies employing a more rigorous research methodology. Although all of the studies reviewed have a number of weaknesses both in relation to their design and analysis of data, there is strong evidence that individual psychotherapy can be an effective form of treatment for people with learning disabilities. Further support for the efficacy of this approach comes from studies outlining group analytic psychotherapy with learning disabled individuals.

3.3. Outcome of group analytic psychotherapy

Given the general lack of therapy resources available to people with learning disabilities group psychotherapy would seem to be an ideal method of providing treatment to a wider range of individuals. To date, there have been few accounts in the literature of the use of group psychotherapy for people with learning disabilities. Hollins (1992) states that this paucity of literature reflects the lack of confidence from clinicians that such an approach can be effective. However, she goes on to state “there is no research evidence that group analytic therapy is not effective” (p141). Three studies outlining the effectiveness of psychotherapy groups will be reviewed.

Gravestock and McGauley (1994) give an account of group psychotherapy for 9 people with learning disabilities. The group met for one hour a week over the course of a year. They indicate that all clients shared similar emotional difficulties at the outset of therapy i.e. interpersonal difficulties in their residential setting, low self-esteem, ambivalence, or confusion about their disabilities and dependency needs. Detailed process issues are reported and are linked to three distinct phases of the therapy which they termed: ‘confusions’, ‘connections’ and ‘painful realities’. In terms of evaluation no objective measures were made and therefore comments on outcome are anecdotal, based on the therapists’ opinions and feedback from clients at the end of the group. The therapists acknowledge that the group structure was unable to contain four clients who left before the group terminated. Of the five clients who remained in the group the therapists comment that they appeared to have developed
their capacities to listen, think and communicate their needs more appropriately. Evidence for how this was generalised outside of the group setting is given. The clients themselves reported missing the group and stated that it had helped them to accept themselves. They conclude by calling for more effective psychotherapy research based on standardised, multi-dimensional assessment and outcome measures that consider the complex health and social-care needs of people with learning disabilities.

Skene (1991) adopted just such an approach to assessment and outcome in a six-month psychotherapy group he facilitated for six people with learning disabilities who presented with difficulties pertaining to sexual behaviour. To increase the validity of his findings Skene employed a comparison group matched for age and intellectual ability. Both groups completed two assessment procedures prior to the commencement of the group and again at termination. The first was the ‘Bell Adjustment Inventory’ (1962), which provides an indication of general mental health and in particular depressive feelings, general nervousness and emotionality. This is thought to be independent of age and IQ level. The second involved completion of a repertory grid, shown by Skene (1973) to provide a measure of therapeutic change. Skene found statistically significant changes on scores for the Bell Adjustment Inventory pre-and post-group indicating a decrease in scores for his clients to within the normal range. He concludes from this that clients were better emotionally adjusted following the psychotherapy group than the control group who had shown a deterioration in emotional adjustment. Statistical investigation of the repertory grids completed pre-and post-group indicated that clients showed a significant need pre-group to change themselves. Following the psychotherapy group, clients were relating themselves more to their family backgrounds and had expanded upon the constructs of self-confidence, aggression and happiness. Statistical findings were backed up with qualitative reports from care staff who reported that clients had become more introspective and calmer, and the clients themselves who thought they had developed a greater sense of optimism and autonomy. Despite the lack of longer term follow-up Skene’s rigorous methodological approach to measuring outcome and clear account of process issues attests to the efficacy of group analytic psychotherapy for people with learning disabilities.
Jones & Bonnar (1996) also attempted to evaluate the outcome of a 12-week psychotherapy group for people with learning disabilities using a range of standardised and qualitative measures, and from a number of different perspectives i.e. client, nurse and therapist. Measures included standardised assessment tools such as ‘The General Health Questionnaire’ (Goldberg, 1972) and ‘The Nurse Observation Scale for In-Patient Evaluation’ (Honigfeld & Klett, 1965) – a validated behaviour rating scale; and measures specifically designed for the group e.g. rating scales of personal interaction, self-esteem and client satisfaction. Detailed process notes are also included in the paper outlining the content of the groups, the dynamic process and problems encountered by the therapists. In terms of outcome it is reported that the results of the questionnaires were inconclusive in that none of them yielded valid results. Qualitative feedback is provided though from the client satisfaction questionnaire. All members rated the group highly and stated that they felt ‘a lot better’ or ‘quite a lot better’ following the group. This however was not reflected in reports from nursing staff who stated that disturbed behaviour had increased over the course of the group in all members. This was thought to be linked to distressing issues being discussed within the group. Jones & Bonnar’s experience of evaluating a psychotherapy group indicates the need to use simple and clear assessment questionnaires which are understandable to people with learning disabilities. It also highlights the difficulty of trying to address complex and painful issues within a short space of time. If the group had run for a longer period Jones & Bonnar may well have obtained more positive and conclusive outcome results.

3.4. Conclusion

Despite the growing interest in the application of psychoanalytic theory and practice to the treatment of people with learning disabilities there remains a paucity of literature attesting to the efficacy of this approach. All of the studies reviewed add weight to the view that people with learning disabilities have the capacity to engage in and make use of psychoanalytic psychotherapy. In terms of evaluating the efficacy of this treatment approach for people with learning disabilities case studies have drawn attention, albeit in a rather anecdotal manner, to the positive gains which can be made within psychotherapy – gains which have been generalised to other areas of clients’
lives and which have been maintained over time. Anecdotal accounts of the efficacy of psychoanalytic psychotherapy have been supported by recent outcome studies which have employed a more rigorous research methodology such as a single-case design. Although often thought to be a long-term and therefore costly treatment, studies have shown that positive changes in clients' behaviour can occur within the space of a few months. However, as demonstrated by Jones & Bonnar's (1996) experience within group analytic psychotherapy, there is a danger of making the duration of therapy too short to bring about positive change.

To summarise then, studies indicate that psychoanalytic psychotherapy can be an effective form of treatment for people with learning disabilities, both in terms of individual and group psychotherapy. Nevertheless, as highlighted by Sarason back in 1951 and again by Hollins and Sinason in 2000, there still remains the need for further well-designed research studies in this area. Perhaps the time has now come for the effectiveness of psychoanalytic psychotherapy for people with learning disabilities to be examined within the framework of a randomised control study.
3.5. References


A Minority Within a Minority: Identity and Well-being Amongst Gay Men with Learning Disabilities
Abstract

People with learning disabilities have long been viewed as belonging to a minority group within society and consequently have to manage the socially constructed stigma attached to such a position. But what of people with learning disabilities who also occupy another socially devalued position by having a lesbian or gay identity? Such people could be viewed as being a minority within a minority. This qualitative study explores the experiences of 10 men with learning disabilities who also have, or who are exploring a gay identity, particularly in relation to how they construct and maintain a gay identity and how they manage threats to their identity that arise from occupying a marginalized social position. Identity Process Theory (Breakwell, 1986, 1996) was seen as being a useful framework for exploring these issues and was therefore employed to guide the content of the interviews on which this study is based. Data were analysed using Interpretative Phenomenological Analysis. The findings from this study point to the social isolation of the participants and their desire for affiliation with gay community contexts. Participants spoke of the restrictions they faced living within care services and how this impacted on their ability to develop and maintain a gay identity. Issues such as the need for gay role models and support in accessing gay community contexts were highlighted. Implications for care services and clinical psychologists working with gay learning-disabled men are discussed.

KEY WORDS: learning disabilities, gay, identity, qualitative, clinical psychology
4.0. Literature Review

4.1. Introduction

“Mentally handicapped people have the same human value as anyone else and so the same human rights”.

(King’s Fund, 1980)

Over the past twenty years or so there has been a dramatic change in the way people with learning disabilities have been cared for. Large long-stay hospitals have been going through a process of closure and people have been resettled back into smaller residential care homes within local communities. Along with the change of setting has come a change of philosophy about the way people with learning disabilities should be enabled to lead their lives. Services for people with learning disabilities now operate within a framework of ‘normalisation’ (Wolfensberger, 1972) or ‘ordinary living’ (King’s Fund, 1980). This framework holds that people with learning disabilities should be afforded the right to an ‘ordinary life’ in the community, making use of local community facilities and participating in community activities.

Implicit in the “principles of ordinary living” is the belief that people with learning disabilities have the same value, the same needs and the same human rights as any other group in society. This also applies to the right to sexual self-expression. These rights are referred to in the United Nations Declaration on the Rights of Mentally Retarded Persons (1971), which states that people with a learning disability have:

♦ The right to receive training in social/sexual behaviour that will open more doors for social contact with people in the community;
♦ The right to all the knowledge about sexuality they can comprehend;
♦ The right to enjoy love and to be loved by the opposite sex, including sexual fulfilment;
♦ The rights for the opportunity to express sexual impulses in the same forms that are socially acceptable for others.
But what of the rights and needs of lesbians and gay men with learning disabilities? Much that has been written on the sexual needs and rights of people with a learning disability has been from a heterosexual perspective (e.g. Craft, 1983, 1994), with homosexuality, until very recently, being seen as a deviant form of sexual expression. Research pertaining to men with learning disabilities who have same sex relationships has tended to focus on the issues of safer sex, HIV prevention and sexual abuse (McCarthy & Thompson, 1994; Murray & MacDonald, 1995; Sobsey, 1994). Lesbian and gay identity in people with a learning disability has so far been a subject that few researchers - either in the area of learning disabilities or in lesbian and gay psychology - have been willing to or felt able to address.

For men without learning disabilities, the process of gay identity formation can have a deleterious effect on self-esteem and psychological well-being (Grossman & Kemer, 1998; Meyer, 1995; Rotheram-Borus, Hunter & Rosario, 1994). What effect then does the construction and maintenance of sexual identity have on the self-esteem and psychological well-being of men with a learning disability who may be experiencing psychological or emotional difficulties as a consequence of already belonging to a devalued group within society?

The main focus of this review will be the literature on gay identity formation and the impact this has on self-esteem and psychological well-being. Within this, early developmental models of sexual identity - although somewhat outdated - will be discussed along with their criticisms. More recent literature examining the way sexual identity interacts with other important identity components and social positions will be reviewed with a particular emphasis on how lesbian and gay identity interacts with ethnic, cultural and religious identity. Identity Process Theory (Breakwell, 1986, 1996) will be discussed as this provides a useful framework within which to consider the identity experiences of gay men with learning disabilities and the strategies employed to manage/alleviate threats to identity. Consideration will be given to the marginalized position of people with learning disabilities in society and the possible implications of this for self-esteem, particularly in relation to having a double minority status. Finally the responses of learning disability services to the needs of their gay clients will be discussed.
4.1.1. Terminology and Definitions

Although various terms have been adopted over the years to describe the users of ‘learning disability’ services (e.g. ‘mentally handicapped’, ‘mentally retarded’, ‘mentally deficient’, ‘intellectually impaired’, ‘developmentally disabled’), the term ‘learning disability’ or ‘learning difficulty’ is currently used by services within Britain and will therefore be used throughout this dissertation.

Luckasson et al. (1992) define a learning disability thus:

♦ Significantly sub-average intellectual functioning (i.e. a composite score of two standard deviations below the mean on an accepted assessment of intellectual functioning); on the ‘Wechsler Adult Intelligence Scale’, a full-scale IQ score of or below 70;
♦ Existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self care, domestic skills, health and safety, leisure and work;
♦ Manifested before the age of 18.

For a person to be described as having a severe learning disability they would need to score below 50 on a standardised test of intellectual functioning and have significant disabilities in the acquisition of adaptive behaviours from early childhood. They may also have additional sensory or physical disabilities (Emerson, 1995).

4.1.2. Epidemiology and Prevalence

The number of people in the UK who have a learning disability is approximately 20 people per 1,000 of the general population with 3 - 4 per 1,000 having a severe learning disability. For an average region of 250,000 people this means that 5,000 people will have a learning disability and of these 750 - 1,000 will have a severe learning disability (Audit Commission, 1987).
It is much more difficult to estimate the prevalence of homosexuality and bisexuality in the general population, as due to social stigma and bias people tend to under-report same sex behaviour or choose not to self-identify as lesbian, gay or bisexual. Prevalence studies have also tended to be based on accounts of sexual behaviour rather than on identification as lesbian or gay. Early research carried out by Kinsey et al. (1948) found that 38.7 per cent of American males between the ages of 36 and 40 reported having had at least one same sex sexual experience, whilst 4 per cent reported being exclusively homosexual in terms of their sexual experience with others. It must be remembered though that this reflects a particular sample of men living in post war America. In a cross-cultural study carried out by Sell et al. (1990) it was found that 11.6 per cent of French and American men and 7.8 per cent of English men reported engaging in same sex sexual behaviour from the age of 15. More recent research suggests that between 7 - 12 per cent of the population admit to having sex with someone of the same sex more than once (Davies & Neal, 1996). However, given the inherent difficulties in conducting these types of surveys, results need to be interpreted with caution.

Although no figures are available on the number of people with learning disabilities who identify as lesbian or gay, or who have same sex relationships, there is no reason to believe that prevalence rates would be very different from those quoted above. Given the possible numbers of people with learning disabilities who may identify as lesbian or gay (a crude estimate, using the above prevalence rates, would put the figure at about 350 people in an average sized district), there is a surprising paucity of literature in this area. Consequently very little is known about the experiences and needs of this client group. However, this is hardly a surprising finding when one looks more generally at the psychological research with people with learning disabilities where issues of gender and sexuality are commonly overlooked (see Burns, 1993). Traditionally, when sexuality is highlighted in the literature, it is generally within a negative context, which tends to frame sexual activity as problematic (e.g. in terms of sexual abuse or sexually transmitted diseases) rather than as a legitimate and positive act. At other times, in common with people with other types of disability, there is an assumption that people with learning disabilities are asexual (O’Toole, 1996; O’Toole & Bregante, 1992). This can also be reflected in practice where the sexual needs of gay clients are routinely overlooked and same sex sexual activities can be viewed as undesirable, inappropriate, or worse still, as a
challenging behaviour in need of correction.

The extant literature on men with learning disabilities who identify as gay will be addressed in more detail in the following section.

4.1.3. Research on men with learning disabilities who identify as gay

As stated earlier most of the published research on men with learning disabilities who have same sex relationships has tended to be within the context of sexual abuse, safer sex and HIV prevention (e.g. Cambridge, 1994; McCarthy & Thompson, 1994; Murray & MacDonald, 1995). Within this literature it is of course acknowledged that men with learning disabilities have sex with other men, both learning disabled and non-learning disabled, but it tends to take as its focus the issues of vulnerability and exploitation. McCarthy & Thompson (1994) state that, “this pattern [of exploitation] has been seen in all the men with learning disabilities who met men for sex in public toilets or similar settings with whom the project has worked” (p.192). The project referred to was an AIDS Awareness/Sex Education Project that carried out safer sex work with people with learning disabilities.

Little has been written on the experiences (either positive or negative) of men with learning disabilities who are trying to construct and maintain a gay identity, or which portrays a gay identity, gay relationships and a gay ‘lifestyle’ for men with learning disabilities in either a non-pathologising or positive light. Moreover, several researchers (e.g. Dowsett & Davis, 1992; Thompson, 1994) have argued that sexual identity concepts for men with learning disabilities are largely irrelevant. This is based on their findings that men with learning disabilities who have sex with men refuse, on the whole, to self-identify as gay. A reason cited for this is the men’s awareness of the societal stigma and prejudice associated with labels such as ‘homosexual’ and ‘gay’. They are consequently unwilling to take on such negatively valued labels for themselves. However, by following such a line, men with learning disabilities who may wish to self identify as gay may be denied opportunities to develop a more positive perception of their sexuality. Refusing to challenge these views and failing to support men with learning disabilities in developing a more positive perception of their sexuality can only serve to reinforce anti-gay prejudice.
and discrimination:

One study that has investigated the experiences of men with learning disabilities who identify as gay and who are exploring their gay identity was carried out by Davidson-Paine and Corbett (1995). They interviewed two young men about their feelings and perceptions of being gay and their experiences of social acceptance, both generally and within the gay community.

From these interviews, Davidson-Paine and Corbett highlight the lack of supportive networks for young men with learning disabilities who are exploring a gay identity. There appeared to be little support available for these men from family, carers or even the gay community itself. A reason given for this is that within the gay community high value is often placed on style, fashion and near perfect models of human beauty, ideals that few men with learning disabilities are able to attain. This is a view shared by Thompson (1994), who states that, “it must be recognised that [men with learning disabilities] would not be easily absorbed into a gay community: they do not belong to the privileged social classes which typify it”. (p. 260). One solution to this difficulty proposed by Thompson, Bryson & Castell (2001) is to create gay community contexts specifically for people with learning disabilities in the form of support groups. Such groups, in their words, “would allow people to process their experiences, know they are not alone and access information concretely” (p. 63).

Although Davidson-Paine & Corbett acknowledge that people with a learning disability are more vulnerable and perhaps open to exploitation from others, they argue that they can be helped to become more assertive and well informed with regard to their sexuality. They posit that the process of normalisation for gay men with learning disabilities needs to include an induction into the gay community in the hope that they will then be able to take a more active role in the forming of their own sexual identity. Similar views are shared by Edmunds and Collins (1999) who, based on their work with a 21 year old gay man with learning disabilities, argue for carers and professionals to help gay clients integrate into gay community contexts as a way of assisting them in the development of their chosen sexual identity. However, people with learning disabilities may find it difficult integrating into gay community contexts where they may be perceived by other
gay men as being different. This may even lead to gay men with learning disabilities being devalued and rejected by other gay men. This will be discussed later in more detail.

In some instances people with learning disabilities not only experience a lack of support from carers in terms of gay identity development, they may also have to contend with care staff's negative attitudes and beliefs about homosexuality.

4.1.4. Attitudes of Professionals and Care Staff

"Whether staff members like it or not, whether they acknowledge it or not, they are enormously powerful in the lives of people with learning disabilities" (Craft & Brown, 1994, p1). As Craft and Brown suggest, the attitudes and beliefs of care staff can have a strong influence on the attitudes, feelings and beliefs of their clients. In this respect carers become important role models for their clients. If care staff hold and express anti-gay attitudes and beliefs, or overlook (either intentionally or unintentionally) the fact that their clients may be gay, it can feel extremely unsafe for people in their care who are gay, or who think they may be gay, to discuss this issue with them openly. In such cases people with learning disabilities may be given the message that homosexuality is not something to be spoken about. However, this can have serious consequences for gay identity development. As Miranda and Storms (1989) state, a pre-requisite for the development of a positive gay identity is communication of one's sexual orientation to others. Furthermore, care staff's negative attitudes towards homosexuality are highly likely to lead to their clients internalising these negative attitudes themselves. Findings from a study carried out by McCabe & Schreck (1992) support this position. They found that 86 per cent of people with a learning disability thought that homosexuality was wrong, compared with 31 per cent who viewed heterosexual intercourse as wrong. This closely mirrors findings from studies examining care staff's attitudes and beliefs. Hingsberger (1993) explored American care staff's attitudes and beliefs about the acceptability of certain sexual activities for people with learning disabilities. He found that whereas 77 per cent of respondents approved of heterosexual "petting" and 72 per cent approved of heterosexual sexual intercourse, only 26 per cent approved of homosexual behaviour between men with a learning disability. Based on anecdotal
evidence, he states that these attitudes were also being mirrored in practice with homosexual behaviour between clients being stopped or even punished. Similar results were found by Jones (1995) who explored the attitudes and beliefs of 150 British care staff and day service staff. She found that barely one third of her respondents had discussed homosexuality with their clients compared to two thirds who had talked about heterosexual sex with their clients. Of more concern, even when staff knew or suspected that a client might be gay, only 31 per cent stated that they had actually discussed the issue of homosexuality with their clients. Reasons given for this reluctance to discuss homosexuality with clients range from a lack of training/experience, lack of support from senior managers to a fear of possible recriminations.

In relation to the attitudes and beliefs of health care professionals, several studies attest to the negative views held by some professionals towards their lesbian, gay or bisexual clients (for example, Annesley & Coyle, 1995, 1998; Dardick & Grady, 1980; Eliason & Randall, 1991; Faugier & Wright, 1990; Irwin, 1992; Robertson, 1998; Wadsworth & McCann, 1992). To cite just one study, Morgan & Nerison (1993) found that up to one third of mental health professionals held negative attitudes towards lesbians and gay men. This can lead to reluctance on the part of lesbian and gay clients to disclose their sexuality to health care professionals for fear of having their homosexuality pathologised or seen as the cause of their difficulties. In extreme cases, gay clients may even refuse to seek professional help for their difficulties. According to Robertson (1998), who interviewed 37 gay men on this subject, “the dominant view was a deep distrust of professional health services” (pg 38).

This raises important issues for gay men with learning disabilities who are trying to develop and manage a gay identity within the context of care services. They are far more likely to be dependent on care staff and mental health professionals for their day-to-day care. Disclosing their sexual identity in such circumstances may feel extremely unsafe, especially if to do so is to jeopardise essential relationships. Furthermore, the internalisation of such attitudes can have a deleterious effect on self-esteem and emotional well-being and further complicate the process of constructing and maintaining a gay identity.
The issue of how gay identity is constructed and maintained will now be discussed in more detail.

4.1.5. Theories of Gay Identity Formation

Many theories have been put forward to try and explain the process of gay identity formation or the “coming out” process. Initial research in this area tended to adopt a stage sequential model or developmental framework suggesting various stages an individual passes through whilst constructing a gay identity (e.g. Cass, 1979; Kleinberg, 1986; McDonald, 1982; Minton & McDonald, 1984; Troiden, 1979; Weinberg, 1983; Woodman & Lenna, 1980). Cass (1979), one of the most influential early researchers in this area, proposed a six stage model where the individual moves from a state of identity confusion through identity acceptance to the end state of identity synthesis, a state where homosexuality becomes integrated into the total self-identity and therefore becomes just one aspect of identity. McDonald (1982) spoke in terms of “milestone events”, suggesting that an individual would usually develop an awareness of same sex feelings at about 13 years of age but would not have achieved a ‘positive’ gay identity until about 24 years of age. The cognitive changes needed to move towards a ‘positive’ gay identity were thought to take place in a developmental fashion.

Garnets & Kimmel (1991), in a review of stage sequential models, found five points that were central to all models:

1. When first becoming aware of same sex sexual attraction, individuals report feeling different and as if in a state of limbo between questioning a heterosexual identity and recognizing a potential gay one. This is what Cass (1979) termed ‘identity confusion’.

2. Individuals need to confront the negative, stereotyped, societal views of homosexuality and transform their view of homosexuality into something positive which can be applied to themselves.

3. Throughout the construction of a gay identity, individuals use a range of
strategies to protect themselves against the social stigma associated with homosexuality. (This will be discussed later in more detail in terms of Breakwell's (1986, 1996) Identity Process Theory).

4. Contact with the gay community whilst constructing a gay identity is important as this helps to foster a sense of group identity, provides role models and diminishes feelings of isolation and difference.

5. Disclosure of sexual identity to others becomes increasingly important. This may begin with disclosure to other gay and lesbian individuals but extends to the need to tell family and friends.

More recently there has been a shift away from the notion of stage sequential models - which have attracted a great deal of criticism - and a move towards more flexible developmental models which view lesbian and gay identity development as a set of tasks and issues that a young person encounters and addresses e.g. self-definition as lesbian or gay, disclosing lesbian or gay identity, development of emotional or sexual relationships with other lesbians or gay men (see Coyle, 1998).

Stage models have been criticised for essentializing homosexuality and for failing to look at how sexuality interacts with other salient aspects of identity e.g. race, culture, ethnicity, religion, class, age and in the context of this study, intellectual ability (see Coyle & Rafalin, 2000; Eliason, 1996; Greene, 1994; Phellas, 2001). Stage models also suggest that once a gay identity is achieved it remains constant and unchanging throughout the life span. Eliason (1996) argues that other developmental processes or transitions throughout the life-cycle (e.g. midlife and older adulthood) can also impact on sexuality, perhaps bringing about further changes in self-identification. For this reason Eliason states that a need has been identified for more fluid and comprehensive models of gay identity formation which take into account not only the various aspects of individual identity but also the sociopolitical/historical context in which an individual negotiates his or her identity.

Several recent studies have explored the issue of gay identity formation with an emphasis
on how this interacts with other aspects of identity (e.g. Coyle and Rafalin, 2000; Greene, 1994, 1997; Phellas, 2001). Greene (1994) argues that sexuality and its meanings are contextual so that what it means to be a lesbian or gay man will be affected by the meaning assigned to sexuality by a specific culture. In some instances this may mean that an individual is forced to choose which aspect of identity is primary (i.e. sexual identity or cultural identity) especially if to adopt a gay identity is to face ridicule and ostracism from one’s own culture.

Within learning disability services, clients are fully immersed in a culture where sexuality is closely regulated and boundaried (Brown, 1994). As discussed above, an assumption is made that people with learning disabilities are for the most part asexual and, where sexuality issues are discussed, this tends to be predominantly from a heterosexual perspective. This perception of an ‘asexual’ learning disabled identity is difficult to reconcile with an identity as a gay man and can impact on an individual’s ability to develop and maintain a gay identity. This in turn can have implications for psychological well-being. The implications for psychological well-being of constructing and maintaining a gay identity will be discussed more fully in the next section.

4.1.6. Psychological well-being, internalised homophobia and minority status

A great deal has been written about the effect of gay identity formation on the mental health and psychological well-being of individuals. However, even when an individual has been able to develop a personally credible way of evaluating gay identity more positively, there is strong evidence to suggest that processes such as minority stress (i.e. stress derived from having a minority status within society) and internalised homophobia continue to impact negatively on mental health throughout life (Hillin, 1993; Meyer, 1995).

4.1.6.1. Gay identity and its impact on mental health

Woodman and Lenna’s (1980) intra psychic model of gay identity formation suggests a four-stage process similar to Kubler-Ross’s (1973) model of loss and bereavement. They suggest that when an individual has been unsuccessful in finding coping strategies for
coming to terms with a gay identity, they enter a stage of depression. Instead of projecting anger at society, their anger and guilt are directed inwards towards the self. This, combined with the real or presumed loss of support from family and friends and lack of alternative sources of support, can lead to severe depression. In some cases, the depression is so severe that the individual contemplates or attempts suicide. Within the literature on gay identity development, suicide is mentioned on an alarmingly frequent basis. Rotheram-Borus, Hunter and Rosario (1994) found that 39 per cent of their young, mostly non-white gay and bisexual male sample had attempted suicide at some point in the past; another 37 per cent had thought about suicide every day for at least a week at some point in their lives; and nearly 60 per cent reported suicidal ideation in the week prior to the study. Trenchard and Warren (1984) in a survey conducted for the London Lesbian and Gay Teenage Group found that 20 per cent of respondents under the age of 21 attempted suicide because they were lesbian or gay. Similar findings have been reported in other studies. The National Lesbian and Gay Health Foundation (1987) reported that 59 per cent of 17 - 24 year old lesbians had contemplated suicide with 25 per cent making actual attempts. D’Augelli and Hershberger (1993) found that 42 per cent of gay American adolescents reported a past suicide attempt. This is considerably higher than estimates of high school suicide attempt rates which ranged from 8 - 13 per cent. Hershberger and D’Augelli (1995), in an attempt to understand factors that affect the mental health and suicidality of gay adolescents, found that mental health was significantly influenced by the interaction between experiences of victimization, family support and self-acceptance.

Coping with a gay identity can continue to have a significant impact on psychological well-being throughout the lifespan. Coyle (1993), in a study of 140 gay men using the General Health Questionnaire (GHQ-30) as a measure of psychological well-being, found that gay men’s scores were comparable with groups of men from the general population who had experienced traumatic emotional life events such as bereavement and divorce. Robertson (1998) reports similar findings from a qualitative study of 37 gay men living in Scotland. Twenty five per cent of respondents had sought contact with medical professions because of anxiety and depression related to their sexuality and the majority of respondents reported some experience of mental distress at some point in their lives related to their sexuality. Some respondents reported using self-destructive strategies for
managing the stress caused by their sexuality, e.g. substance misuse.

Both Coyle and Robertson state that it is not being gay per se that has a detrimental effect on mental health but rather the experiences individuals have in coping with their gay identity. Robertson states that depression in his respondents was mostly related to the stress of coping with sexuality in environments that were perceived as hostile and isolating. Other factors found to affect mental health were lack of supportive networks, rejection from family and friends, and negative social representations of homosexuality - all of which can lead to internalised homophobia and social marginalisation.

4.1.6.2. Internalised homophobia

Internalised homophobia refers to the direction of anti-gay societal attitudes and beliefs inwards towards the self. Isay (1989) states, “at some point in intensive psychotherapy, every gay man expresses unhappiness and dissatisfaction with his homosexuality. The socialization of every homosexual involves internalisation of the social animosity he experiences” (p.120). The nature of this ‘social animosity’ or negative societal attitudes can be at several different levels. Davies (1996), drawing on Allport’s (1954) scale of prejudice, highlights three levels of prejudice experienced by gay men:

1. Verbal rejection: hearing others verbalize their dislike of lesbians and gay men; hearing anti-gay jokes and experiencing derogatory terms e.g. poof, queer.

2. Discrimination: being denied equality of treatment in areas such as education, employment and housing.

3. Physical attack: experiencing or hearing about ‘gay bashing’, murders and rape of lesbians and gay men.

Exposure to anti-gay attitudes and beliefs begins early in a child’s life, often well before they begin to question their own sexual identity. Within society, anti-gay messages abound and are often observable within families (see Pilkington & D’Augelli, 1995), schools (see Rivers, 1999; Trenchard & Warren, 1984), media and in the case of people
with learning disabilities, within the services in which they live. At the time when an
individual first begins to question their sexuality and first thinks about applying the label
‘gay’ to themselves they also begin to apply the negative attitudes and beliefs which
accompany such labels to themselves. This can lead to the process of self devaluation
(Breakwell, 1986), which in turn impacts negatively on self-esteem and psychological
well-being. This has been shown to remain an important factor in psychological
adjustment throughout an individual’s life (see Gonsiorek, 1988; Hetrick & Martin,
1984). In relation to men with learning disabilities, Thompson (1994) found through his
work with men who have sex with men that many were aware of terms such as ‘gay’ and
‘homosexual’ (as well as more derogatory terms). However, they overwhelmingly
construed these labels negatively and on the whole refused to apply them to themselves.

The patterns by which homophobia is internalised and the consequent effects on
psychological adjustment have been clearly outlined by Hillin (1993). He suggests that
when faced with homophobia or oppression gay men will internalise this. In some cases
where the individual has positive images of a gay identity, this will militate against the
internalised oppression, therefore lessening its detrimental effect on psychological well­
being. For other gay men, internalised oppression can lead to lower levels of self esteem
which in turn leads to further deleterious effects on psychological well-being and
behaviour. Hillin suggests that, in order to cope with this, the individual may turn to
forms of self-abuse such as substance misuse, self-harm and, as mentioned above, suicide
attempts. Other individuals may cope with internalised oppression by suppressing their
sexual feelings and by refusing to disclose their sexuality to others. Again, such coping
strategies can have a negative impact on both psychological well-being and physical
health. Rivers (1999), in a study of 119 lesbians, gay men and bisexual men and women
who had been harassed whilst at school, found that those who had not disclosed their
sexual orientation to others reported being more uncomfortable about being lesbian, gay
or bisexual than those who had disclosed. Furthermore those who had not disclosed their
sexuality to others were found to have more symptoms of post-traumatic stress disorder
(as a consequence of earlier harassment) than those who were open about their sexuality.

There is therefore overwhelming evidence to suggest that belonging to a minority group
within society, in this case by having a lesbian or gay identity, is linked to higher levels
of emotional distress and mental health difficulties. But what of individuals who have membership of more than one socially devalued group e.g. gay individuals who belong to an ethnic or cultural minority or who have a learning disability? Could they be exposed to a double discrimination or face multiple oppressions?

4.1.6.3. Double minority status

Greene (1994) states that “the stress of coming out may be particularly intense for members of ethnic minority groups, because they must manage multiple oppressions” (p.249). Greene argues that in cultures where there is a strong emphasis on parenting and continuation of a family line or where there are strong norms about gender-appropriate behaviour or where there are strong religious beliefs, being openly lesbian or gay may bring disapproval or even ostracism from both family and ethnic community (see also Carballo-Diequez, 1989; Espin, 1987; Morales, 1990). Therefore once lesbians and gay men from ethnic minority backgrounds have ‘come out’ as lesbian or gay, they may lose the support that comes from belonging to a cohesive social group. This can lead to a sense of isolation, feelings of estrangement, anger, frustration and increased vulnerability to psychological distress. This can be exacerbated by the reactions of lesbian and gay communities which tend to be predominantly white and in some instances discriminatory against people from ethnic minority groups (Chan, 1992; Cochran, 1988; Dyne, 1980; Phellas, 2001).

What little research that has been carried out with gay men with learning disabilities suggests that they potentially face the same multiple oppressions as gay men from ethnic minority backgrounds. Davidson-Paine & Corbett (1995) found that gay men with learning disabilities face ostracism from their own communities when they disclose their gay identity and they may also face rejection from gay communities because of their difference, as the following quotation from the study’s data set highlights:

Q: What would you label as being a greater disability, your learning/physical disabilities or being gay?
A: That’s difficult. I was kicked out of the Mormon Church for being gay. I’ve been seen
as different by the gay community for being disabled and having a learning difficulty. I am put in a very low power base in relation to physical disability because I have a learning disability. People take no notice of me because I have a mild learning difficulty and a physical disability occasionally. 

(Davidson-Paine & Corbett, 1995, p.148)

This comment points to the potential isolation and loneliness faced by gay men with learning disabilities who may face rejection from a group (in this case, gay communities) that they are relying on to compensate for rejection by other groups (e.g. family, carers, ethnic/cultural communities). Rejection from gay community contexts makes it difficult for these men to satisfy a need for affiliation – something that may be a particularly salient need for learning disabled gay men. However, even if men with learning disabilities are able to access gay community contexts, they will still belong to two socially devalued groups and will therefore need to find ways of managing the concomitant stress this may cause. This issue will be addressed in the next section.

4.1.7. Protective factors and managing threats to identity

Being a gay man or a gay man with multiple minority status (e.g. a gay learning disabled man) does not invariably lead to psychological distress or poor psychological adjustment. There are factors which can act to safeguard mental health or which act as mediating variables to protect psychological well-being when an individual is constructing and managing a gay identity.

4.1.7.1. Protective factors

One factor cited in several studies which protects psychological well-being is support from gay communities or contact with other lesbians and gay men (Grossman & Kerner, 1998; Plummer, 1984; Woodman, 1992). Such contact can counteract the feelings of isolation, loneliness and estrangement experienced by many men during the process of gay identity development. Socializing with other gay men can provide much needed role models and ‘mentor relationships’ (Plummer, 1984). ‘Mentor relationships’ refer to established members of gay communities acting as sources of support and advice to newer members. Plummer states that contact with other gay men provides a role model
for homosexuality, which helps militate against negative societal views of homosexuality. He argues that this allows the individual to form a more favourable image of homosexuality and therefore helps the individual to take on homosexuality as a salient aspect of their identity. Without positive role models of homosexuality the individual may find self-labelling as a gay man distressing.

Having a supportive network of gay friends can also alleviate some of the anxiety and fear attached to disclosing sexuality to family and non-gay friends (Gluth & Kiselica, 1994). However, such protective factors may not be readily available to gay men with learning disabilities. As mentioned above, learning disabled gay men are not always welcomed into gay community contexts and this is assuming that they even get the support needed from carers to access such venues. Even within care services, there is a reluctance on the part of gay identified staff to be open about their sexuality – further denying gay clients access to gay role models. This may be linked to fears that they will be seen by others as coaching men with learning disabilities to be gay, and the threat of discrimination and recrimination from colleagues (Rensenbrink, 1996).

Another factor thought to be crucial to psychological adjustment is support from significant others e.g. family, friends and teachers (Frable, Wortman & Joseph, 1997; Grossman & Kemer, 1998). In the case of people with learning disabilities, support from carers would also be of paramount importance.

In reality, it is likely that several factors interact to either protect against or predispose the individual to psychological distress. Frable et al. (1997), in a study of 825 men, examined the inter-relationships between ‘cultural stigma’, ‘personal visibility’, ‘community networks’, ‘positive identity’ and ‘positive self perceptions’ (i.e. higher levels of self-esteem, increased emotional well-being and lower psychological distress). ‘Personal visibility’ was defined as being visibly gay i.e. by wearing certain clothes and jewellery and visiting venues associated with the gay community, and ‘positive identity’ as having a positive impression and sense of importance about the group memberships one has. It was found that ‘community networks’ and ‘personal visibility’ were linked to a ‘positive identity’ which in turn was linked to ‘positive self perceptions’. Unsurprisingly they also found that higher levels of ‘cultural stigma’ were negatively
related to 'positive self perceptions'. An unexpected finding, however, was that 'personal visibility', despite having a positive relationship with 'positive identity', had a negative relationship when compared directly with 'positive self perceptions'. This means that participants who had the highest levels of self-esteem and well-being and the lowest levels of psychological distress were those who were less visibly gay. Although this finding is not adequately explained by Frable et al., it is likely that participants who are more visibly gay are also more likely to be exposed to 'cultural stigma'. Frable et al. conclude by stating that avoiding stigmatising experiences and lessening personal visibility are direct paths to positive self-perceptions i.e. better psychological adjustment as a gay man. However it is questionable how easy it would be to avoid pervasive anti-gay prejudice totally, and moreover how desirable it would be for gay men to have to reduce their ‘personal visibility’.

A potentially useful framework for making sense of both the identity experiences of people with learning disabilities in general, and more specifically the identity experiences of gay men with learning disabilities, is Breakwell’s (1986, 1996) Identity Process Theory (IPT). This is a social psychological model of identity which aims to combine both intrapsychic and socio-political processes. According to Breakwell, the main purpose of this model is to facilitate the exploration of threats to identity and the strategies employed to cope with these. IPT has been used successfully to understand threats to identity that arise from ‘coming out’ as a lesbian (Markowe, 1996), and to make sense of the identity experiences of Jewish gay men (Coyle & Rafelin, 2000).

4.1.7.2. Identity process theory (IPT) and managing threats to identity

IPT is grounded in the assumption that identity structure is governed by the processes of assimilation-accommodation and evaluation. Assimilation refers to the incorporation of new identity elements within an existing identity structure; accommodation refers to the changes that need to occur in the existing identity structure in order to absorb new elements; and evaluation refers to the allocation of value to identity elements. These processes are said to operate according to four main identity principles: self-esteem, continuity, distinctiveness and self-efficacy, which define desirable end-states for
identity. Within IPT, self-esteem refers to a sense of personal worth or value; continuity refers to continuity across time and context; distinctiveness refers to a sense of personal uniqueness; and self-efficacy refers to a sense of personal competence and control. Although these are the major identity principles, others have been identified in work with specific populations. Markowe (1996), from her work with lesbians suggested that authenticity/integrity and affiliation were salient principles for her participants in their construction of lesbian identity.

Threats to identity are said to occur when the processes of assimilation/accommodation and evaluation are prevented from operating according to the identity principles. For example, in relation to people with learning disabilities, the prevalent negative social representation of learning disability could mean that it is difficult for individuals to assume an identity as learning disabled without this seriously compromising self-esteem and self-efficacy and giving them a negative and socially devalued distinctiveness. The problem lies with the evaluation process; to protect against identity threat, the individual must find a personally credible way of evaluating learning disabilities more positively or else avoid taking on learning disability as a salient part of their identity.

Coping strategies - defined as any activity that serves to remove or modify threat to identity - are employed by the individual to ensure that any threats are transient (Breakwell, 1986). Coping strategies can operate at a number of different levels: intra-psychic, interpersonal and intergroup. Intra-psychic strategies operate at the level of cognitions, emotions and values, for example denial of the threat; interpersonal strategies rely on changing relationships with others and include strategies such as isolation (e.g. avoiding contact with others) and passing (e.g. gaining access to a group or social category by camouflaging one's group origins); intergroup strategies operates at the level of group membership and includes coping strategies such as joining with others with similar predicaments to form a support or consciousness raising group.

Breakwell makes the point that an identity element can only pose a threat to identity if the individual is aware that the identity element is relevant to them and carries a negative social evaluation. Studies examining individuals' awareness of their learning disability and the subsequent impact on self-esteem have produced conflicting findings. The
literature pertaining to this will be addressed in the next section.

4.1.8. Self-esteem and learning disability

It is now generally accepted that people with learning disabilities belong to a marginalized and devalued group within society and that consequently they would experience lower levels of self-esteem and higher levels of psychological distress compared to those without learning disabilities. This is thought to be a direct result of belonging to a socially stigmatised group which faces multiple oppressions. However, recent research into the area of self-esteem and learning disabilities (e.g. Finlay & Lyons, 1998; Jahoda, Markova & Cattermole, 1988; Szivos-Bach, 1993) has conflicted over how people with learning disabilities perceive themselves and the effect this has on their self-esteem. Before this research is examined in more detail, research exploring the general public’s perception of the term ‘learning disability’ will be discussed.

4.1.8.1. The effect of labelling

Historically many different labels have been attached to people with learning disabilities as a form of diagnostic classification. It has been argued that, in so doing, attention is drawn to the ‘special needs’ of this group who can then be offered the specialist treatment they require (Franco, 1982; Rowitz, 1981). However, as well as drawing attention to a group’s ‘special needs’, labels can also take on negative connotations, especially if the group they are applied to has a marginalized social status. In the past, terms such as ‘imbecile’, ‘moron’ and ‘idiot’ were all legitimate ways of medically classifying people with a learning disability and had precise technical and legal meanings. Nowadays these labels are more commonly known as terms of abuse. In an attempt to reduce the stigmatising effect of labels, terminology to describe this group of people has been changed over time. Hastings and Remington (1993) carried out research asking college students to evaluate different terms currently in use to describe learning disabilities and challenging behaviour e.g. ‘developmental disability’, ‘mental deficiency’, ‘difficult behaviour’, ‘aberrant behaviour’. Although it was found that terms such as ‘learning difficulty’ and ‘challenging behaviour’ were rated more favourably than labels such as ‘mental retardation’, virtually all the terms assessed carried negative rather than neutral or
positive connotations. In terms of the effect that negative connotations can have on people with learning disabilities, Hastings and Remington conclude by saying that "we can ill afford to ignore the power of the words that we use to describe them" (p. 247).

Although it would appear that society continues to view labels such as 'learning disability' in a negative way, a vital consideration of this study is whether people with learning disabilities apply these terms to themselves and, if so, whether they also perceive them in a negative way.

41.8.2. The self-concept of people with learning disabilities and its relationship to stigma and self-esteem.

Several studies have investigated the issue of self-concept, stigma and self-esteem in people with learning disabilities. Researchers such as Davies and Jenkins (1997), in a study of 60 people with learning disabilities, found that the majority of participants did not have access to the cultural discourse about them and thus did not understand the terminology used to refer to them. They argue that there is consequently no reason to believe that these labels have been internalised or that self-identity was affected by them. However, the level of intellectual impairment experienced by the participants is not made clear in this study. It may be reasonable to assume that individuals with a more severe learning disability may not have the cognitive abilities needed to understand the terminology used to describe them or the negative associations attached to these terms.

Jahoda, Markova and Cattermole (1988) interviewed 12 people with a mild learning disability to explore their views on stigma and handicap. They found that all participants were aware of the stigma associated with being identified as someone with a learning disability. Moreover, all of the participants described how they had to cope with the consequences of this stigma in their everyday lives. Reports were given of being teased or bullied by non-handicapped peers and five participants reported being treated differently to non-handicapped siblings at home. Ten of the participants were aware that there was a stigma attached to attending day services for people with learning disabilities and that non-handicapped others negatively stereotyped those who attended a day centre. Despite this understanding and acknowledgement of stigma, only three of the people
Interviewed perceived themselves as being "essentially different" from non-handicapped people. So although in this study people acknowledged the stigma attached to having a "learning disability" label, the majority did not allow this to influence their self-concept. Mest (1988) states that being aware of stigma is not the same as internalising stigma. He argues that people develop a positive sense of themselves from their personal experiences rather than by simple internalisation of negative societal representations. This would suggest that, in some way, people with learning disabilities are protected from negative, stigmatising experiences, or use coping strategies to protect themselves.

This view is supported by research carried out by Szivos-Bach (1993) and Finlay and Lyons (1998). Szivos-Bach asked 50 students with a learning disability to complete a self-esteem and social comparisons procedure. She found that students who perceived the greatest stigma also had the lowest levels of self-esteem, the lowest ideals for themselves and also felt themselves least likely to fulfil their aspirations. She also found that some students engaged in social comparisons with others as means of safeguarding their self-esteem. Finlay and Lyons (1998) found that the majority of people with learning disabilities whom they interviewed did not spontaneously use the label 'learning disabilities' to describe themselves. However, when directly asked, two thirds of participants agreed that the label referred to them. They also found that global self-esteem was not correlated with learning disability group evaluation even when the group evaluation was negative and the individual accepted group membership. It was found though that those who denied the label felt significantly more competent than those who did not.

The relationship between self-concept, stigma and self-esteem is therefore a complex one. Although people with a learning disability may understand the stigma attached to belonging to a devalued group within society, this does not automatically lead to lower levels of self-esteem or higher levels of psychological distress. This may be because individuals with a learning disability are employing some form of coping strategy to protect themselves from threats to identity or because people with a learning disability are protected from the damaging effects of labelling and stigma by the positive influences of parents and carers (Davies & Jenkins, 1997; Todd & Shearn, 1997). For gay men with learning disabilities, the identity threat may be greater than for other learning disabled
people, with the generally negative social evaluation of gay sexuality also threatening self-esteem, giving negative distinctiveness, and perhaps also compromising continuity in the ‘coming out’ process.

4.2. Aims of present study

The present study aims to build upon the work carried out by Davidson-Paine and Corbett (1995), by exploring in depth the experiences of men with a learning disability who are trying to construct and maintain a gay identity. Many theories have been put forward to explain the process of gay identity formation and the process of integrating sexual identity with other salient aspects of identity. However, to date there has been little research examining how gay men with a learning disability manage the process of gay identity formation, particularly within the context of care services, or how gay identity and learning disabled identity are incorporated into global identity.

It has been shown that the process of gay identity formation can have deleterious effects on mental health, with the majority of gay men experiencing some form of psychological distress related to their sexuality at some point in their lives. In extreme cases, this has resulted in suicide and attempted suicide. Internalised homophobia and minority status can both contribute to the stigma and emotional distress experienced by gay men. As recognition of identity threat is a key issue, this study aims to look at how gay men with a learning disability perceive and interpret their status as both gay men and men with learning disabilities, and the effects this has on their emotional well-being. It also aims to explore the experiences gay men with learning disabilities have had of societal and institutional responses to their sexuality and the effects this has had on their global identity and psychological well-being.

Although this study is not setting out to test identity process theory (Breakwell, 1986, 1996) this will be used as a framework within which to consider the identity experiences of gay men with learning disabilities and to explore how they manage threats to identity (see Coyle & Rafelin, 2000; Devine-Wright & Lyons, 1997; Johnson & Robson, 1999; & Markowe, 1986, for examples of other studies which used this theory in the same way).
4.3. Method

As very little is known about the experiences of gay men with learning disabilities, the aim of the study was to explore in depth participants’ accounts of being gay learning disabled men. As such, it was decided that a qualitative methodology would provide the flexibility and scope needed to provide a rich source of data.

4.3.1. Participants

Attempts were made to recruit men with a learning disability who either self-identified as gay or who were exploring a gay identity. Although no limits were placed on the degree of learning disability, given the nature of the interview procedure all participants needed to be able to communicate verbally. Participants were recruited from the London area, four through a support group facilitated by the researcher for gay men with learning disabilities and others through contacting voluntary agencies for people with learning disabilities and community health teams for people with learning disabilities. There were no restrictions placed on the age of participants (apart from being over the age of 18), where the participants lived (i.e. independently or in residential care homes) or the daytime occupation of participants (i.e. working or attending day care facilities). Ten men agreed to participate in the study.

In the analysis the names of participants have been changed and any identifying information has been altered or omitted in order to preserve participants’ confidentiality.

4.3.2. Interview Schedule

The interview schedule (see Appendix One) was developed from a review of the literature and consisted of a number of open-ended questions. After demographic information was collected (see Appendix Two), the interview schedule asked about the context in which gay identity was developed; initial disclosure and reactions to this; subsequent disclosures; community networks; experience of cultural stigma and internalised homophobia; experiences of ‘passing’ as heterosexual; positive self perceptions; effect of being learning disabled on emotional well-being; and finally reflections on the process of
participating in the interview. The questions were used to guide the conversation and not in a way that would impose a rigid structure on the interview. This, along with the open-ended nature of the questions, ensured that participants could influence the direction of the interview. As the questions asked about many highly personal issues of a sensitive nature, and given the researcher's background as a clinical psychologist, an interactional style of interviewing derived from counselling was employed (Coyle, 1998). However, the researcher was mindful during the interviews of not adopting a therapeutic style and when necessary participants were advised of other avenues of support available to them.

4.3.3. Procedure

All potential participants were sent an information sheet (see Appendix Three) outlining the aims of the study and what participation would involve. If individuals were then interested in participating in the study, they were met briefly by the researcher to discuss this in more detail and to sign a consent form (see Appendix Four). Ethical approval for this study was obtained from both the University of Surrey's Advisory Committee on Ethics and the researcher's NHS Trust's ethical committee (see Appendix five).

Participants were interviewed face to face by the researcher at a place of their choosing. Interviews were audio-taped and lasted between one and two hours. Participants could ask for a break during the interview at any time. Some participants were interviewed over two sessions to help with concentration and to decrease the likelihood of fatigue. All taped interviews were transcribed verbatim by the researcher before analysis took place.

4.3.4. Methodological considerations given to interviewing men with learning disabilities

Particular consideration needed to be given in this study to the fact that participants had a learning disability. In order to make the interview process as effective as possible in terms of tapping into rich sources of data but also as comfortable and stress-free as possible for the participants, a range of strategies was adopted. Firstly the style of the interview was as relaxed as possible, adopting a conversational/interactional style and using a minimum amount of structure and formality (Wyngaarden, 1981). Participants were given the option of choosing a venue for the interview. When they did not want
interviews to take place within their homes, the researcher ensured that a comfortable and private space was made available that was easily accessible for them.

In order to minimise acquiescence and over reporting associated with yes/no questions and the tendency to choose the second option in either/or questions, open-ended questions were employed wherever possible (Sigelman, Budd, Spanhel & Schoenrock, 1981a, 1981b). When questions appeared too complex for the participant to understand or when it was unclear if participants had fully understood a question, they would be re-phrased or asked again in a simpler format. The researcher would also frequently summarise his understanding of what had been said and ask for confirmation that this was correct.

Prior to the interview, the researcher also had a discussion with participants' carers wherever possible to ascertain any communication or sensory difficulties the participant may have. In such cases advice was sought from carers on the best way of communicating with the participant.

Participants were also assured that their decision to participate or not participate in the study would in no way affect the ongoing care they were receiving from services. This was particularly important for those men who knew the researcher in the context of an ongoing support group for gay learning-disabled men. To reduce the likelihood that participants would respond to questions in a socially desirable way and to minimise any defensiveness arising from the sensitive nature of the questions, the researcher was open with participants about his own sexuality and where appropriate answered any questions they asked of him. Finally, due to the sensitive nature of the interview, the researcher offered to meet with participants at a future date if they wanted to discuss issues arising from the interview process. Two participants took up this offer.

4.3.5. Data Analysis

The transcribed interviews were analysed using interpretative phenomenological analysis (IPA) (Smith, 1996; Smith, Flowers, & Osborn, 1997; Smith, Jarman & Osborn, 1999). This is a relatively new procedure which has been used principally within the domains of health and counselling/clinical psychology (see Coyle & Rafalin, 2000; Golsworth &
Coyle, 1999, 2001; Jarman, Smith & Walsh, 1997; Knudson & Coyle, 2002; Osborn et al., 1998; Senior et al., 2002; Smith et al., 1997; Smith, 1999; Turner & Coyle, 2000). The main aim of IPA is to explore in detail the participant’s view of the subject being investigated rather than producing objective statements or quantifiable themes. In this respect it adopts an “insider’s perspective” (Conrad, 1987) to the extent that this is possible. According to Smith et al. (1999), IPA recognises that the research exercise is a dynamic process. In this respect, the analytic process is influenced by and dependent upon the interpretative framework of the researcher. The approach is thus both phenomenological and interpretative in nature. Whilst IPA does not claim that an individual’s thoughts are transparent within verbal reports, analysis is undertaken with the assumption that meaningful interpretations can be made about that thinking (Smith et al., 1997).

As it is important within qualitative research to be as transparent as possible about the process of analysis (Smith, 1996), the analytic strategy adopted in this study will be outlined. The first stage of the analytic procedure involved repeated readings of each transcript in turn, in order to become as intimate as possible with each account. During these readings and re-readings notes were made in the left-hand margin of the transcripts about initial thoughts, key phrases, processes or preliminary interpretations about the data. With each re-reading new insights emerged and it became possible to begin making connections and associations between different aspects of the data. For each transcript these connections and associations were used to abstract emerging themes for that transcript. These were written in the right hand margin. Once a transcript had been analysed in this way, the list of emerging themes for that transcript was written on a separate sheet of paper in order to look for connections between them. Themes connected together were then grouped together and regarded as higher order themes. Care was taken at each stage to ensure that themes could be illustrated by the data set. Any themes that were not clearly represented in the data set were rejected. This process was repeated for each transcript in turn, with the higher order themes from previous transcripts being used to guide the analysis of subsequent transcripts. However, this did not preclude the possibility that new themes or connections might emerge from transcripts. In this case new emerging themes would be noted and previously analysed transcripts revisited to see if the new theme was also represented in the data from these interviews. Once each
transcript had been analysed in this way, the final list of higher order themes from each transcript were brought together into one grouping and consolidated, using a similar process as before. This produced a list of superordinate themes or master list of themes for the whole group. Extracts from the transcripts were grouped under each theme to ensure that the theme was represented in the data. Again, themes not clearly represented in the data were rejected. The superordinate themes were then ordered in such a way as to produce a logical and coherent narrative. No attempt was made to quantify themes, as the aim of IPA is to produce an analytic narrative reflecting the nature and range of experiences rather than the quantification of these experiences. Although commonalities between transcripts were highlighted, differences were not ignored as these often provided insights into the complexity of the phenomena under investigation and the processes operating within them.

Inevitably such an analysis is subjective in nature as it is based within the researcher’s own interpretative framework. This may raise questions about its validity. Different researchers may have prioritised other aspects of the data, arriving at different interpretations. For this reason, it is important to note the interpretative framework of both the researcher and his research supervisor who oversaw the analytic process. In this study, the researcher’s interpretative framework has been shaped by his training, practice and knowledge of clinical psychology, particularly working with a learning disability population; experience of working psychotherapeutically with gay men who are learning disabled; and personal experience of being a gay man and the process of gay identity formation. It was hoped that any idiosyncratic interpretations or “blind-spots” would be compensated for by the research supervisor’s position as a gay man and social psychologist who has published widely in the area of lesbian and gay psychology. It was therefore hoped that the researcher would be sensitive to a wide range of themes emerging from the data and be mindful of preconceived expectations and attributions. Although the researcher and the research supervisor had some ‘insider’ understanding of many of the contexts and situations described by the participants, it needs to be borne in mind that neither had an experiential perspective as learning disabled men. This may mean that some of the subtleties and nuances of participants’ experiences of being learning disabled men were overlooked in the analysis.
In relation to the evaluation of the research, traditional criteria such as reliability and validity are inappropriate as they assume a certain degree of objectivity and disengagement from the analytic process (Henwood & Pidgeon, 1992). Instead, qualitative researchers have suggested the evaluative criteria of internal coherence and persuasiveness (Elliott, Fischer, & Rennie, 1999; Smith, 1996). This is achieved by 'grounding in examples' i.e. by ensuring that themes and interpretations are illustrated by extracts from the data. This hopefully allows the reader to decide on the persuasiveness of the analysis for themselves. In the current study, extracts from interviews are used whenever possible to illustrate interpretations. In these quotations, empty brackets indicate where material has been omitted; information appearing in square brackets has been added for clarificatory purposes and ellipsis points (...) indicate a pause in the flow of participants' speech.
4.4. Analysis

4.4.1. Demographic Information

The mean age of participants in this study was 37.3 years (range 27 – 54; SD 9.0). In terms of living arrangements, four men (40%) lived in a staffed residential care home, two (20%) within their family home and two (20%) independently in the community. All but one of the participants had lived at some point in their lives in residential/hospital care, either in the community or in a long-stay hospital. All participants were either currently receiving or had received in the past services from community teams for people with learning disabilities and were therefore known to have a diagnosed learning disability.

Eight participants (80%) were in paid employment (either full-time or part-time), one (10%) attended college and one (10%) had both a part time job and attended college. All participants stated that they only had sexual relationships with men. Five of the participants (50%) had been in a same sex relationship in the past; one of these men (10%) was in a relationship at the time of interview.

4.4.2. Outline of analysis

The analysis section will explore issues such as development of a gay identity, disclosure of sexuality to others, stigma, need for affiliation and support networks - issues not necessarily specific to gay men with a learning disability. This will be in order to highlight similarities and differences between the experiences of gay men with a learning disability and those of gay men in general. It will then address issues more specific to gay men with learning disabilities such as self-esteem, restrictions of being in care, and types of support needed. The issue of how gay men with learning disabilities manage threats to identity will be discussed in a separate section - although reference will be made to this throughout the analysis section.
4.4.3. Developing a gay identity

As the issue of gay identity development has been discussed at length in the literature (for example see Cass, 1979; Kleinberg, 1986; McDonald, 1982; Troiden, 1979; Weinberg, 1983; Woodman and Lenna, 1980), it will not be examined in depth here. Suffice it to say accounts given by the men in this study are consistent with the studies mentioned above, which were carried out with gay men in the general population.

In common with many gay men, the majority of participants in the current study acknowledged an awareness of their sexuality from an early age on the basis of attraction and/or behaviour:

Um, I remember when I was about 12 or 13 um, I was sort of like, I knew I was gay straight away cause I used to um have like all these posters from ‘Smash Hits’ and they used to be like men posters and I used to put them up on my wall. I knew straight away that I was gay. (Ray)

I think, I think 14. Then I start to kiss a bloke. (Stuart)

Although both Ray and Stuart appear to have developed a strong, almost unequivocal sense of their sexuality from an early age, others such as John, went through a period of uncertainty akin to what Cass (1979) termed ‘identity confusion’:

Um, that’s when I decided if I wanted to be married and have children. The next day I’m gay. The next day I want to get married and have children. [] Um, I been confused from about 12 years old. (John)

One area worthy of further discussion - and something that is not often referred to in other studies - is the sense that some participants tried to make of the origins of their sexuality. As mentioned earlier, people with learning disabilities, because of their inherent vulnerability and reliance on others for care, can often be the victims of sexual abuse. Several of the participants thought that the sexual abuse they had experienced in their lives was formative in the development of their gay identity. For example, John, having been sexually abused as a child whilst in residential care, traced his gay identity back to an “unhappy childhood”:

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Um, some people, um, cannot help themselves being gay because of their childhood and all that. Um, they may have had an unhappy childhood like myself.

For others like Jason and Graham, sexually abusive experiences later in life have for them become linked with the origins of their gay identity.

Interviewer: How old would you say you were Jason when you first found yourself attracted to men?
Jason: When I got hurt by them [ ] They abused me so I thought I'd be gay.

Interviewer: Can you tell me about the time when you first thought you might be gay?
Graham: Well at the time my mates, you know, my mates at that time, my mates pushed me into it. They just gave me a cup of coffee at their place. It was drugged with sleeping tablets. [ ] They were too strong for me, you know, one holding my legs down, one holding my arms down and they just whipped my clothes off.

Experiences did not necessarily have to be sexually abusive for participants to view them as being significant in the development of their sexuality. Ray, for example, traced the origins of his sexuality back to childhood experiences with his sister:

Well when I was more younger, when I was like eleven, my sister used to dress me up in girls' clothes and that's um, because before that I was alright, I wasn't gay. [ ] I sort of found out afterwards when she dressed me up in girls' clothes that it turned me, not going out with girls, it turned to be the other way like gay and all that.

In these accounts, gay identity has been construed by the participants as being the result of something, usually negative, which happens or is done to them earlier in life. In so doing, there is a sense in which they are trying to develop a narrative which explains and makes sense of but does not blame them for their gay identity. It could be argued that the participants are trying to protect themselves from the stigma or identity threat inherent in having a gay identity. This is in accord with the coping strategy described by Breakwell (1986) as 'reconstrual' or 're-attribution'. By employing this strategy the individual exonerates themselves from any responsibility for being in the threatening situation, as
they attribute their position to external forces beyond their control. However, in this case, by employing such a strategy, there is a danger that gay identity can become negatively evaluated by the individual.

The issue of stigma attached to being both a learning disabled man and a gay man will be discussed in the next sections.

4.4.4. Stigma and learning disability

One of the principal aims of the current study was to explore in detail if men who identify as gay and who have a learning disability experience a 'double discrimination' from mainstream society for occupying two stigmatised positions. The majority of participants in this study reported experiencing some form of prejudice or discrimination related to their learning disability at some point in their lives. For some participants, this took the form of overt verbal abuse:

Children took the mickey out of you [ ] Keep calling ‘spastic’ and that. ‘Cripple’ and that sort of thing. (Jonathan)

They used to call me ‘moron’ and ‘divvy’ and all that. (Mark)

Er, well I don’t know really, they come out and say (...) I don’t know. ‘Are you a spastic?’ sometimes they say that. (Peter)

For other participants, the discrimination took on a more subtle form but was still perceived by them as being related to their learning disability, as the following extract from Ray highlights:

Ray: Well some of my friends treat me OK and they treat me the same and like a couple of times before when I sort of gave out my carer’s phone number these girls who live in Wandsworth they would sort of approach me and treat me differently just because I’ve got a shaking problem.

Interviewer: How would they treat you differently?
Ray: Well the things they would come out with. They sort of like, once I went to
their house and they kept saying. Oh, they was standing behind this curtain and they were laughing and that’s one thing that really hurts me the most is laughing about my learning difficulty. Um, they sort of said ‘Oh we’re not laughing at you we’re laughing at this old man.’ And I’m sure they’re laughing at me because they’re hiding behind the curtain and they won’t say it to my face.

As can be seen from Ray’s comments, being the butt of others’ ridicule, especially when these are supposed friends, can be extremely upsetting and hurtful to the individual. Other participants who had encountered similar experiences described them as “not nice”, “not very good”, “awful”, and admitted to feeling “a bit hurt” by them.

This raises an important issue within identity process theory (Breakwell, 1986, 1996) and one that is particularly pertinent to people with learning disabilities. For something to pose a threat to identity, there needs to be awareness that the identity element is relevant to them and also carries a negative social evaluation. Studies in this area (see Davies and Jenkins, 1997; Finlay and Lyons, 1998; Jahoda, Markova and Cattermole, 1988) disagree over the issue of whether people with learning disabilities understand the terminology used to refer to them, can understand the stigma which has been attached to these labels, and consequently internalise this stigma. The comments above would suggest that these men are not only aware of the negative evaluations made by others about learning disability; they are also aware that these evaluations are being made of them. This in turn can then lead to an awareness of ‘difference’ from the mainstream and can reinforce the individual’s minority status. This is highlighted in the following comments made by John:

<table>
<thead>
<tr>
<th>Interviewer:</th>
<th>Was it OK that people were looking at you, did that feel alright?</th>
</tr>
</thead>
<tbody>
<tr>
<td>John:</td>
<td>No.</td>
</tr>
<tr>
<td>Interviewer:</td>
<td>You didn’t like that?</td>
</tr>
<tr>
<td>John:</td>
<td>No.</td>
</tr>
<tr>
<td>Interviewer:</td>
<td>What was it about that you didn’t like?</td>
</tr>
<tr>
<td>John:</td>
<td>I didn’t like people looking at me all the time. The way I act and all that.</td>
</tr>
<tr>
<td>Interviewer:</td>
<td>Why do you think they were looking at you?</td>
</tr>
<tr>
<td>John:</td>
<td>The way I act.</td>
</tr>
<tr>
<td>Interviewer:</td>
<td>How were you acting?</td>
</tr>
</tbody>
</table>

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John: Um, I think the clothes I was wearing yeah. [ ] Well not clothes, but I think the way I acted really was different.

In this extract John was talking about the way he was treated by gay men in a gay club he frequented – a club he had initially been unsuccessful in gaining entry to because of his lack of conformity to what could be termed ‘gay norms’ (this issue will be addressed more fully in a later section). This quotation highlights John’s awareness of his difference from those around him and the subsequent feelings this evokes within him.

Awareness of difference is an issue that several other participants commented on and highlighted through the use of words such as ‘normal’ and ‘proper’.

Interviewer: What would be different if you didn’t have a learning disability?
Mark: I would be more like normal other men.
Interviewer: Do you perhaps feel that you’re not like normal other men?
Mark: No, I feel different.

Stuart acknowledges his difference by identifying himself as someone with Down’s Syndrome, something he equates with not being normal. He reaches this conclusion based on an account he has been given of his birth.

Stuart: Me told I got a problem as a baby. Mum have me and as a baby me pop out but not breathe properly, got a chest infection. Then the doctor came around “You got a Down’s Syndrome child (...) You’ve got a not normal Down’s Syndrome child” [ ]

Interviewer: [ ] How do people react to you now when they know you’ve got Down’s Syndrome?
Stuart: With the normal, with the normal, with the normal people.

Although Stuart has acknowledged his difference from others, it is interesting that his perception is that others react to him as they would to “normal people”. It may well be the case for Stuart that others do not treat him differently because he has Down’s syndrome. However, given society’s general reaction to obvious difference, this would appear to be unlikely. A possible explanation is that Stuart is employing a coping strategy to protect himself from identity threat. Breakwell (1986) talks of ‘denial’ as
being a commonly employed deflection strategy. Although Stuart is not denying his difference, he may well be denying that there is a threat attached to this difference by rejecting the idea that being a man with Down’s syndrome represents a social stigma. By doing this he would be safeguarding self-esteem and protecting himself from a negative and socially devalued distinctiveness.

Given these experiences of identity threat, it is not surprising that several of the participants employed strategies to protect themselves from their negative and stigmatising experiences. For Graham, this involved keeping his learning disability secret from others:

Nobody knows. That’s confidential as well. It’s my problem not theirs and I don’t tell them [ ].
They can’t do nothing. So what’s the use of telling them? It’s nothing to do with them anyway.

Such a strategy of secrecy perhaps works well for men like Graham who have a mild learning disability but would perhaps be less successful for those with a more marked or obvious disability. There is also a danger that Graham would be thrown into a position of identity threat if others did find out about his learning disability. To protect himself further from a position of identity threat, Graham also employs a re-attribution strategy. He sees his learning disability as being the result of inadequate teaching and therefore as something that is outside his control and is not an essential, inherent part of him:

Graham: [ ] As the teacher was so slow we all suffered up there anyway.
Interviewer: [ ] How did you suffer?
Graham: Going into a classroom where the teacher’s on the phone the whole time. How d’you expect us to learn if they have to go from the classroom all the time once the phone rings? Every hour, every hour of the day the bloody phone rings and someone has to answer it - which she did (...) I can’t read or write anyway. My writings a mess, I can’t even write a lot down.

Ray, on the other hand, accepts his learning disability as being part of who he is and therefore as something immutable:

It’s just the way I was born and I mean if I shake it’s just part of my handicap really. It’s just a part of me really. Can’t really get rid of it.
Breakwell (1986) refers to this form of acceptance as a ‘fundamental change’. She states that in assimilating ‘stigmatised’ components into the identity structure the individual has to deal with losses to continuity, distinctiveness and self-esteem, although in so doing the threat to identity and its concomitant anxiety is negated.

Although Ray has accepted his learning disability as being part of who he is, this does not necessarily mean that he has found a personally credible way of evaluating learning disability more positively. Ray’s focus on the physical limitations caused by his learning disability (i.e. his shaking) rather than the cognitive or intellectual limitations may be his way of trying to evaluate learning disability more favourably. Even so, the following quotation highlights Ray’s perception that being a person with learning disabilities is not the same as being a “normal” or “proper person”

Yeah sometimes, like when I was um, when I lived here now with my carers I thought to myself that I don’t really like having this learning difficulty. I just wish I was a normal, young human being and not have all these learning difficulties bothering me all the time. There used to be a time where I used to keep shaking a lot and I used to sort of think to myself I didn’t really want to have this shaking problem and that I used to want to be um, like a proper person and not have shakes [ ] Why can’t I sort of be like a normal person and not have all this shaking problem?

This view is echoed by several other participants who expressed ways in which they believed things would be different or better for them if they were not learning disabled. Issues such as being able to go to pubs and clubs, travel independently (especially at night), read and write, and have more confidence and better-developed interpersonal skills were mentioned.

It is now widely held (Breakwell, 1986; Finlay, 2001; Mest, 1988) that being aware of stigma alone is not enough to place an individual in a position of identity threat. Rather, it is the personal experiences people have which modulate threats to identity. From the above comments, it can be seen that these men have not only been made aware of others’ negative evaluations of learning disabilities; they have also had direct experience of this and, to a certain degree, have experienced these as threats to identity.
4.4.5. Stigma and gay identity

As well as managing the negative evaluations and stigma attached to having a learning disability, the men in this study, in common with other gay men, also need to manage the stigma associated with having a gay identity. In this respect they can be said to have a double minority status and must therefore manage multiple oppressions (Greene, 1994). This is highlighted in the following comments from Ray:

They sort of approached me in the street a couple of times, a long time ago and took the mickey cause when I was out by myself the girls, a group of girls used to say “Are you a man or a woman?” When I had my hair long and then sometimes they always used to start on me about er, my personality and why am I different from other people and why I shake so much.

As above though, for something to pose a threat to identity, the individual must realise the identity element is relevant to them and also carries a negative social evaluation. On the first count, the majority of men in this study (90 per cent) identified themselves as being gay. One participant did not self-identify as gay at the time of interview although acknowledged that he was exploring a gay identity. On the second count, the majority of participants in this study expressed an awareness of the negative evaluations made by others about homosexuality. For Stuart and Graham, negative messages about homosexuality were gleaned from the media, and in particular from television. In the first quotation, Stuart is talking about a character from a soap opera:

Yeah Tony fights these two youngsters because they call him gay, poofster, poofster. (Stuart)

Well sort of yeah, cause I sort of like heard it that some people on the news, it used to be on the telly and they used to say some gays got beaten up because they like came out of their school and they used to sort of approach someone and taunt them and they sort of got bullied by them. (Graham)

Jason, on the other hand, was exposed to negative messages about homosexuality directly from a group of friends who wanted him to join them in “gay bashing”:

Some people that are gay bashers say come with me and then they beat you up. Gay bashers, you think they are gay and go with them and then get beaten up. [ ] My friends outside, gay bashers.
They said do I want to go gay bashing and I said I don’t want to do it.

Awareness of prejudice directed towards gay men is not restricted to instances of verbal or physical abuse. Often prejudice can be experienced in the form of inequality and discrimination. In the following quotation, Jonathan expresses some understanding that gay men are being treated differently from others:

Jonathan: I’d like, I’d like, I’d like to see gay men get into Parliament and voting for this right.
Interviewer: The right for what?
Jonathan: Get more money for them. Tony Blair’s not doing a lot for them, the gay men.

As well as being aware of societal prejudice directed towards lesbians and gay men, the majority of men in the study had also experienced some form of anti-gay prejudice or verbal abuse directly. For some, like Jack, anti-gay verbal abuse came from strangers:

Yeah, because sometimes I walk down the street and they always say “You’re a fucking queer”.

In these instances, Jack thought he was being picked out as a gay man because of his appearance and in particular the way he dressed. This is akin to what Frable et al. (1997) termed ‘personal visibility’, a factor they linked to higher levels of ‘cultural stigma’.

For Ray, the experience of prejudice came from a close friend who suspected him of being gay after he tried to defend gay men:

And he said to me “Well are you gay? Is that why you’re trying to stick up for them? Because if you are I don’t want you in my house”.

This places Ray in a difficult and unenviable position. On the one hand he wants to champion the cause of gay men but in so doing he risks jeopardising a long-standing and important friendship. The issue of disclosure and its impact on essential relationships will be addressed in a later section. Another participant, Peter, experienced anti-gay jokes whilst at work. As his work colleagues did not know he was gay, Peter had some difficulties knowing how to react to these jokes:
Yeah, it feels difficult 'cause I don't really like it. I like it up to a point but then (...)

Peter resolved his difficulties by pretending at work that he was not gay, a strategy referred to in the literature as ‘passing’ (Breakwell, 1986; Goffman, 1963). This strategy involves keeping one’s group origins or the source of the threat hidden from others. In this case, by pretending to be heterosexual.

The above quotations indicate that gay men with learning disabilities are not only aware of, but are also the victims of, anti-gay prejudice. Moreover, this takes the same form as prejudice directed towards other gay men and is at all three levels of prejudice described by Davies (1996), i.e. verbal rejection, discrimination and physical attack.

As would be expected, participants’ reactions to this prejudice encompassed feelings of sadness, hurt, fear and anger. For Jack, his anger was so intense that he spoke of wanting revenge by setting fire to the perpetrators’ houses:

Well I got a bit upset about it and I said I’m going to set, I’m going to set fire to their houses.

Other participants responded to anti-gay prejudice by taking direct action. For Peter, this meant informing his employment officer of anti-gay remarks made by his boss. For Ray, strategies for dealing with anti-gay comments included directly confronting others about their prejudice. In the following quotation Ray is responding to a friend who had just told him that he had attacked a gay man after being winked at by him:

I felt really upset because it’s not really for people to make judgement on them. It’s sort of er, for guys who are gay to go out and not for people who are straight beating them up for the hell of it because they think gays give people AIDS because of it. I mean I said to him what about women? And he said, “Oh women are alright. If one woman gets off with another woman that’s OK” he said. I said ‘What about men getting off with other men?’ And he said, “That’s wrong, men are supposed to be on this earth to go out with women.” I said, ‘Not necessarily - if they want to be like that.’

By challenging and confronting others’ prejudice, participants are achieving what Garnets and Kimmel (1991) would consider to be an important factor in gay identity development i.e. confronting the negative, stereotyped, societal views of homosexuality and
transforming their view of homosexuality into something positive which can be applied to
themselves.

4.4.6. Accessing gay community venues

An important factor in the development of a lesbian or gay identity cited in several
studies (see Garnets and Kimmel, 1991, for a review of these) is contact with lesbian and
gay communities. It is argued that contact with such communities helps to foster a sense
of group identity, provides role models and diminishes feelings of isolation and
difference. Frable et al. (1997) found that having strong gay community networks and
personal visibility (i.e. accessing gay venues) were strongly correlated with higher levels
of self-esteem and lower levels of psychological distress. All participants in the current
study were aware of the existence of gay venues such as pubs and clubs, and spoke of
wanting to be able to access them. As Graham stated when asked if he ever went to gay
venues, “No, [ ] but I wouldn’t mind”. The importance of accessing gay venues was
highlighted by Ray, who had also never been to a gay venue. In the following quotation
he articulates what it would mean to him to be able to do so:

I’ve never done this before but I want to because it’s a good experience, beginning to sort of, go
out by myself and do all this before I hit thirty. Cause I’ve got two years to go before I hit thirty
and I don’t want to sit at home not doing anything with my life and thinking oh I’ve been missing
everything in my life.

Those who already accessed some gay community contexts spoke of wanting to be able
to access a wider range of venues. However, one issue that arose for many participants
was knowing where to find them.

Interviewer: Would you like to be going to more gay pubs?
Paul: Yes, can you find out for us, can you find out? [ ] To start with you can help
me, help me find out, find out for us where they are and let me know.

For Paul, one way to find out about gay venues was to ask someone to find out for him.
This strategy can of course only be successful if the person being asked has access to this
information or is willing to find out. In this case, Paul was advised to discuss this at the

gay support group he attended. Other participants used a variety of methods to try and find out for themselves. Mark adopted the strategy of going out and asking passers-by where to find a gay pub:

Interviewer: How did you find out where the gay pubs were?
Mark: I just had a look around and asked people.
Interviewer: Which people did you ask?
Mark: Just people on the street [laughs]

Mark’s laughter perhaps indicates his awareness that such a strategy carries risks, particularly if he had approached the wrong people on the street. Jonathan decided he would telephone directory enquiries to find out about gay venues and, although this proved to be partially successful, he was only told about one pub in central London - too far away for him to access alone (the need for support in accessing gay venues will be discussed later). Other participants such as John and Peter telephoned Lesbian and Gay Switchboard and were given details of pubs and, in the case of John, information about a group for gay men and lesbians who were “just coming out”. Jason, on the other hand, found out about gay venues through reading the gay press. Although a successful strategy for Jason, other participants highlighted difficulties with this, such as not being able to buy gay magazines in their local shops, finding the magazines too expensive to buy or not having the reading skills necessary to understand the magazines.

Even when participants knew where gay venues were, they often experienced difficulties in accessing them. For some, difficulties arose because the venues were located some distance from where they lived and their learning disability impeded their ability to travel independently:

I, I haven’t been to any pubs (...) I haven’t been anywhere because like it’s too far for me, too far from my, too far from where I live. (Paul)

No, there are some up London but I couldn’t travel up there[ ] in case I get lost. (Graham)

I did try that one, you know that one on Shepherd’s Bush Green. You know what time he say it finish? Two o’clock in the morning. Now how do you get back from there to here? (Jonathan)
Even when participants were able to travel independently to gay venues, they still experienced difficulties accessing the venues alone. Several participants mentioned feeling nervous or scared of going into a pub alone for the first time—a feeling that many gay men would share. Some participants, however, were able to overcome their fear:

It was a bit scary really and I was a bit nervous. (...) But after a bit I got used to it. (Mark)

But for others such as Ray, the fear was so great, that even after he had arrived at a gay pub, he still could not go in:

I sort of just had this feeling as soon as I got to the doors. I thought ‘Should I go in?’ And I just set foot in one door and then there was another door but I just couldn’t go through with it. I was just too scared.

For Ray, as with some other participants, the fear appeared to be linked to not knowing what to expect when he entered a gay pub:

I kept thinking if I go to the West End they’ll probably be taking drugs and all that. And I got a bit scared about that for going in the first time.

The inability to access a gay venue appeared to have a profound impact on Ray’s emotional well-being and on his self-perception:

It felt a bit like I was lost and all that but I couldn’t sort of figure out which way to turn. And I felt sort of like lonely, because I felt stupid as well, because I knew that if I had gone in it would have changed my life and it would have helped me. But I knew I couldn’t do it. I just felt sort of um, scared and stupid, really silly.

This highlights the importance placed by almost all participants on being part of a gay culture, whether this is to combat feelings of isolation and loneliness or to meet a need for affiliation with other gay men. What is evident from the above accounts though, is the support and help needed by many of the men to access gay venues and to feel part of gay communities. However, as will be explored later, there is a difference between being able to access venues and having a sense of belonging, or feeling of membership. The issue of support will now be discussed in more detail.
4.4.7. The need for support

For people with learning disabilities, particularly those living within care homes, needing and receiving support from others is an integral part of their daily lives. For some, community life would be impossible without carers - paid and unpaid - to support them in activities of daily living. For some time now, services have realised that their duty of care towards clients must take into account their varied cultural needs (see the Government White Paper, Valuing People, 2001). Such a duty of care should of course extend to meeting the needs of lesbian and gay clients in their care. For the participants in this study, the experiences of support from carers have been variable, ranging from little or no support to active support, i.e. being accompanied to gay pubs and clubs.

For some participants, the support from carers appeared to be more emotional in nature and was restricted to talking about things or advice giving, rather than being of a more practical nature:

Jason: Supportive, yeah they were supportive.
Interviewer: Did they do anything to help you?
Jason: Just go along to men’s group and enjoy yourself [ ] We sit down and chat and she said, “We’ve had this talk before, don’t get worried, I’ll under...” She’s here to help us.

The men’s group referred to by Jason was a support group for gay men with learning disabilities facilitated by the researcher. In the above extract, Jason conveys the sense that he finds his carers supportive and is able to talk to them about things that are troubling him. Similarly Ray finds his carer to be supportive and understanding:

She said to me that she’s very supportive about me being gay cause she said she knows what it feels like being in my shoes, er, being gay cause she said, er, that she doesn’t mind me being this way and she doesn’t mind me being gay. She’s sort of understanding about it and she knows what it’s like.

Although finding his carer supportive, Ray goes on to ask an important question - who is best placed to provide help and support to a gay man? He questions just how much a
heterosexual carer really does know and understand about the needs of a gay client:

I don't know how she knows what it's like cause she's not gay herself. She's married to a guy and she said she's got some gay friends and all that but she said she does know what it's like.

Ray's observation also resonates with the on-going debate about how easy or appropriate it is for heterosexual psychotherapists to work effectively with lesbian or gay clients (see Milton, Coyle & Legg, 2002 for a detailed account of this). As Ray also experienced, a carer's lack of knowledge and familiarity with gay culture and gay behaviour can impact on the opportunities available for exploring and developing a gay identity:

They said to me "You're not allowed to go out by yourself to those clubs". Er, because they think that if I go by myself there will be like five other guys and they will probably pin me down and rape me and stab me afterwards. And I said 'Well it's not like that' and they said, "Well you don't know what it's like because you've never been". And I don't think they know what it's like really because she's married and so she's not gone herself so she won't know what it's like.

This quotation also highlights the risk that heterosexual carers may portray gay behaviour in a negative light, perhaps giving subtle messages about the appropriateness of certain activities. Jonathan experienced similar reactions when he told his female carer, that he had been 'cottaging' at Heathrow airport. Cottaging is the term used to describe men meeting sexual partners in public toilets. Although technically illegal, Davies, Hickson, Weatherburn and Hunt (1993) found, in a study of 403 men, that nearly one third of their sample met sexual partners in this way:

Jonathan: I told Claire about it.
Interviewer: What did Claire say about it?
Jonathan: It's wrong doing it [ ] I've not been doing it now. I've been good.
Interviewer: So is it bad to do it?
Jonathan: Bad.

For Jonathan, disclosing this behaviour to someone who is not au fait with gay culture means that he has been given a negative message about an activity considered to be acceptable by many gay men. Although it could be argued that Claire was acting in Jonathan's best interests (and had a duty of care to do so), he was not in this situation
given advice on less risky ways of meeting his sexual needs.

Peter’s experience of living in a care home with heterosexual carers is somewhat different. Not only was he able to talk to his key-worker openly about being a gay man, his key-worker also offered more practical support by accompanying him to gay clubs:

Peter: Um, well, um, well, my key-worker, in the past we’ve gone to a couple of gay night clubs up London. He’s quite supportive.

Interviewer: [ ] And you said you went with your key-worker, is he a gay man?

Peter: No.

However, not all heterosexual carers would feel comfortable accompanying clients to gay venues, Peter being the only participant who mentioned a carer doing this. This does not however, mean that other participants’ needs for support were ignored. In a number of cases, instead of providing the support themselves, several of the participants’ carers arranged for them to be offered support by gay professionals or organisations. Jonathan’s key worker arranged for a gay identified professional to accompany him to a gay club:

Jonathan: I used, I used to go to a gay men’s club in King’s Cross with a bloke [ ].

Interviewer: [ ] Who did you go there with?

Jonathan: A bloke from around here.

Interviewer: Was it someone who lived here or a member of staff?

Jonathan: He was an outside one. Claire knows him.

Paul’s carer arranged for him to meet with someone from an organisation specialising in sexuality issues for people with learning disabilities. The worker from this project accompanied Paul to a gay pub and also managed to link him into a local gay men’s group:

First time I met Daniel. First time I met Daniel, I’d not met Daniel before. It was er, what’s her name, the name of the woman who gave the, one of the staff who. What’s her name now? [ ] Daniel, I see every day, every Monday. I see him every Monday, he’s fantastic. He’s very nice. He’s been very friendly, very nice to me [ ] It was Ann’s idea, Ann’s idea. She told me to find out. [ ] Er, first I went with Daniel once, with Daniel once, Daniel took me once.

Paul manages to express here something of his feelings about the importance to him of a
person like Daniel. In the following extract Mark also conveys the importance to him of his relationship with a community nurse who is a gay man – someone who can offer emotional as well as practical support and advice

Mark: The only gay friend that I got is Simon, that’s all I’ve got. So only one, one person, that’s all I’ve got.
Interviewer: It sounds like he’s an important person.
Mark: He is cause he’s my community nurse, my key worker and all that, so he helps me out. [ ] He helps me out with my problems and he helps me out, now he’s helping me on my diet. And he helps me out talking about relationships and sex things too. Having sex with men and how to do it safely and all that. He’s liked worked with me on that.

After being let down by a lesbian college friend who had promised to give him details of a gay club, Ray also turned to his community nurse (a gay man) for support and advice:

So I’ve asked her but every time I kept asking her she’d say “Oh you can come” and every time I sort of said to her, oh, er, ‘I’ll give you like £10 if you know whereabouts it is’ [a gay club] she wouldn’t tell me. So I thought that’s a load of good, nobody’s going to help me. So I thought the only way to do it is if I find out something about it for myself. So in the end I asked Andrew [community nurse] if he’s got a gay magazine about gay men and he said “Yeah there is” and sort of gave me one. And now all I have to do like, I looked through it and it was really nice like all these phone numbers of men who are gay. I found out where the gay men are through the magazines.

One would have to question how easy or appropriate it would be for a gay man with learning disabilities to speak openly about sex and gay relationships to either a female or heterosexual male carer and how easy it would be to ask them for specific support and advice. It would seem therefore that gay identified professionals such as Simon, Andrew and Daniel who are ‘out’ to their clients can provide important sources of support and guidance for gay men with learning disabilities. In addition they can provide contact with other gay men, something that is so often lacking for gay men with learning disabilities living in care settings. This type of relationship is often referred to in the literature as “mentor relationships”. Plummer (1989) views such contact with other gay men as invaluable in providing models for gay sexuality which can challenge social stereotypes and permit the development of a view of gay sexuality as legitimate and rewarding. As
will be discussed in more detail later, this is particularly important for men living in care
settings who may be exposed to negative messages from carers about gay sexuality (see
Hingsberger, 1993; Jones, 1995).

5.4.8. Sense of belonging/need for affiliation

As discussed earlier, all participants spoke of their desire to be part of a gay culture or
gay community. However, as many of the participants experienced, feeling part of a gay
community or having a sense of affiliation involved more than just accessing gay venues.
Awareness of difference and issues such as other gay men’s reactions to them played a
big part in how accepted or welcome participants felt. As John experienced, being
different and not conforming to others’ expectations about gay men initially led to him
being excluded from a gay club he wanted to enter:

John: Yeah because at first they turn me away, um, and that’s the reason why I went
back every week and then they knew my face and let me in.
Interviewer: That’s interesting. When you first went they turned you away?
John: A couple of times yeah.
Interviewer: How did they turn you away?
John: “Can you move to the side?”
Interviewer: \[ \] What did you do?
John: They asked me to leave.
Interviewer: What did you think about that?
John: Awful
Interviewer: And why do you think they wouldn’t let you in John?
John: Like before, the way I act (...) the way I walk, the way I talk.

For John, his persistence eventually paid off but at the cost of knowing his initial
exclusion was related to difference. This experience also had lasting implications for
John as it made him wary of trying to access other gay venues for fear of being denied
access:

John: I think I would like to go to more but I think I’m worried they won’t let me in.
Interviewer: Because of your past experience?
John: No, because of the way I look, the way I act towards people.
Interviewer: So that stops you from going to other places?
John: Yeah. But if someone could come with me then I would be happy.

For Jonathan, the fear of being denied access to a gay venue was also something that had been troubling him:

What would, what would happen if they don’t let you in?

Such experiences and concerns can only add to the already heightened anxiety about entering a gay venue for the first time. However, even when participants had negotiated entry to gay venues, they appear to have received a mixed reception from other gay men. For some participants, the reception they received was neither welcoming nor hostile and in this respect was probably akin to those of many gay men without learning disabilities:

Interviewer: How do the other people there react to you?
Paul: Alright. They talk to you sometimes and then they ignore you sometimes.
Interviewer: So sometimes they talk to you and sometimes they ignore you?
Paul: Ignored me.

Interviewer: What was it like talking to the men?
Jonathan: Nice(…)
Interviewer: How did they react to you?
Jonathan: Alright(…)
Interviewer: Did they talk back?
Jonathan: They’d talk back sometimes, they talk back sometimes eh? Yeah they do.

Interviewer: When you went to the gay pub before, how did the other gay men there treat you?
Jason: They never approached me.
Interviewer: Would you like them to have taken notice of you?
Jason: No, I didn’t fancy none of them (…)

For other participants such as John, the responses received could be described as overtly hostile and threatening:

John: When someone came up to me and said “Why are you here?” and all that.

Interviewer: Did that feel uncomfortable?
John: Yeah.

In this case, it would seem that John’s right to be in the club was being questioned by other gay men. These participants’ experiences of neutral or hostile reactions from other gay men are consistent with Davidson-Paine and Corbett’s (1995) findings that the gay community offered little support to the men with learning disabilities in their study. One reason they posit for this is the high value placed by gay communities on style, fashion and beauty - ideals that few gay men with learning disabilities are able to attain. This sense of not measuring up and of being different has been highlighted above by John in his comments on the way he looks, acts and talks. Peter was also aware of the difficulties he had of fitting in within gay venues. This appeared to be linked to his uncertainty about how to behave:

Interviewer: And do you feel confident when you go to gay bars and clubs?
Peter: No, I feel like that I stick out in the crowd. I’m happy about being there, don’t get me wrong.

Interviewer: Can you say a bit more about why you think you stick out?
Peter: (...) Well (...) um, I don’t know, I just feel that I do. I just feel like um, I’m stuck in some sort of corner somewhere. Yeah, I don’t feel like I know where to put myself.

Peter’s difficulties may be the result of a general social awkwardness and perhaps general lack of interpersonal skills related to his learning disability or it may be more situation-specific, i.e. not knowing how to behave in gay settings as highlighted further in the following extract:

No, I don’t feel shy with gay men. No, it’s just er, I don’t know how to start a conversation off with people, how to speak to people, other gay men, no.

Here Peter is highlighting his difficulties talking to other gay men. This may reflect a lack of shared experiences and interests with non-learning disabled gay men, making it difficult to find a common ground. Again, the lack of access to gay venues, gay press, and the internet means that men with learning disabilities are perhaps less well informed about ‘gay culture’ and interests than most other gay men.
Mark hinted in an earlier extract at experiencing the same difficulties in gay venues of not understanding the 'social rules' or norms when he said, "I was a bit nervous, didn't know what to do". Again this highlights the importance of 'mentor relationships' in informing gay men with learning disabilities about gay cultural and social norms in order to help them understand more about gay 'social rules' and behaviour. In so doing, 'mentors' may also help gay men with learning disabilities to have a sense of fitting in and belonging to gay communities.

Breakwell (1986) speaks of group support as being an important inter-group strategy for managing threatened identities. She states that the formation of a group of people sharing the same type of threat (in this case, being both gay and learning disabled) can be a cure for isolation and provide social and informational networks. However, as will be discussed a little later the support needed and desired by many of the participants does not necessarily have to come from gay professionals or carers; it could just as easily be provided by a network of gay friends.

Despite the difficulties experienced by some of the participants in feeling accepted and welcomed by other gay men and the concerns raised about fitting in, participants also spoke of their enjoyment in being part of a gay culture and of the positive experiences they had had. For example:

I was going out every night and I was happy because I was going out every night enjoying myself
[ ] I’m happy, yeah, because if you go to the pub what’s gay they’re nice to you “Hello darling, what would you like?” But if you go to a normal pub they say “Half a lager that will be 52,52”, because they’re not nice to you when you go to, when you go to, when you go to a gay pub they’re more nice to you. (Jack).

It’s nice in there, lovely, nice friendly people [ ] Alright fine, I love it, I enjoy it very much. It’s good fun. Nice to have a chat with nice people you meet. (Paul)

Really good, make new friends. I say hello. That’s really good I like it. (Stuart)

I just wandered in, sat down with a drink, and then this guy comes up to me and tries to chat me up [laughs]. (Mark)

Although a number of the participants were regularly going to gay venues, this tended to
be on their own. Very few of the men had a network of gay friends they could call upon or socialise with. The issue of gay support networks will be addressed in the next section.

4.4.9. Gay support networks

For people with learning disabilities, the question of support networks raises an important issue. It is not uncommon for people with learning disabilities to have few or no friendships outside their immediate care or family environment. Within residential settings, support networks tend to be established between care staff and residents rather than between residents themselves (Chappell, 1994; Srivastava, 2001). As people with learning disabilities have little or no choice in where and with whom they live, they could be living with others with whom they have little or nothing in common. This is particularly pertinent to gay men with learning disabilities who often find they are the only gay resident living in a care home, usually without gay support workers. This is highlighted in the following extract from Jonathan:

Interviewer: Do you have any friends at the moment who are gay?
Jonathan: No.
Interviewer: Do you know of any other gay people?
Jonathan: None in here, no.
Interviewer: What about outside of here?
Jonathan: No, not outside. Only neighbours around here.
Interviewer: Is there anywhere where you do know gay people?

Similar to Jonathan, a number of other participants spoke of having no gay friendships and of not knowing any other gay men. Unfortunately the opportunities for gay men with learning disabilities to meet other gay men and to develop friendships are somewhat limited. There are few established support groups and organizations for gay men with learning disabilities (Thompson et al., 2001) and, as mentioned before, several factors make accessing gay venues difficult for men with learning disabilities. Unfortunately these are the very places where gay friendships are most likely to be formed and maintained. A lack of meaningful contact with other gay men, especially other gay learning-disabled men, can lead to a sense of frustration and a feeling of isolation as the
following quotations demonstrate:

I’m sick and tired of going to a club on my own, all on my own and I need someone to come with me. (John)

I’m, I’m, I’m lonely. I’m lonely. (Stuart)

Paul saw moving to a house where he could live with other gay men as a way of meeting his need for affiliation and as a way of combating his feelings of isolation:

Interviewer: So if you weren’t living in a group home things would be different?
Paul: Yeah.
Interviewer: Can you say a bit about how they would be different?
Paul: Find a nice home, nice, nice gay men or something like that. That would be very nice.
Interviewer: So you’d like to live with some other gay men?
Paul: Hm, away from, away from the other lot. They drive you mad.

All of the men in the study spoke of wanting to have a wider network of gay friends. Issues such as having more in common with gay men, being able to talk openly about sex and relationships, moral support in accessing gay venues and a shared understanding of what it is like being a gay man were all cited by participants as reasons why they consider it important to have gay friendships. Ray eloquently summed up his reasons for wanting gay friends in the following way:

Well sort of like being friends with a group of gay men, sort of going like, sort of having, like and we could sort of be the same. You know, like people have the same personality and they sort of like, if you talk about gay stuff they’ll understand about it because they’re like the same as you and all that. And they would sort of be understanding, what it’s like to be gay or homosexual [ ] It will be really exciting to be friends with other homosexuals and gays. If I went to clubs and all that and I met them and we told each other our roots and all that. [ ] We could sort of go out to places that we’ve never done before and sort of go to lots of different areas where we could sort of er, not get started on, where people will accept us for who we are.

However, even when participants did have gay friends there were often restrictions on how often they were able to see each other. For some, geographic location meant that it
was often difficult to visit or see friends on a regular basis. This was the case for Peter who lived in Surrey but had gay friends in Brighton and London. For others, the restrictions of living in a care home meant that access to gay friends was limited. This issue will now be addressed in more detail.

4.4.10. Restrictions of being in care

In common with the majority of people with learning disabilities, all but one of the participants in this study were either living in residential homes, with paid carers or had previous experience of living in a care setting. All of the men who had experience of care settings stated that this had impacted on their ability to live as an openly gay man. One factor mentioned by almost all men was the lack of privacy which comes from living in communal housing. For Paul, this meant the constant feeling that others knew his business and that it was impossible to keep things private from either staff or other residents:

All the Cedars [name of care home] know. The Cedars knows everything, everyone knows. I tell you the whole of the staff at the Cedars knows everything. [ ] All the other people, the residents know everything about where I go, who I go out with, this and that. It just drives me mad, I don’t like it. It’s very embarrassing for me, it really is. I wish people would just leave me alone for five minutes and give me space [ ] It’s none of their business at all - it’s private.

Paul highlights in this extract just how upsetting and frustrating it is for him believing that everyone knows his business. In reality, this is the experience of many people with learning disabilities living in residential homes who are used to having daily reports written about them by care staff. In addition to the emotional consequences of having little or no privacy, living in a care setting can also impact on the individual’s ability to develop relationships. Several participants mentioned that they did not or would not feel comfortable taking partners back to where they lived because of the lack of privacy. For example:

Interviewer: Would you be able to bring people back here?
Peter: If I wanted to.
Interviewer: Have you ever done that?

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Peter: No.
Interviewer: What’s stopped you do you think?
Peter: (...) Nothing’s stopped me. I’d just feel uncomfortable doing it I suppose.
Interviewer: What would feel uncomfortable about doing that?
Peter: Um (...) [Interview was interrupted at this point by someone coming into the room without knocking] I don’t know, it’s just not as private as I would like.
Interviewer: That demonstrates it really [referring to interruption] was that what you meant?
Peter: Yeah.

For Peter even having the space within his home to talk to someone in private and without interruption was difficult. One can only imagine how much harder it would be to have privacy with a sexual partner or boyfriend. For most people the only private space they have is their bedrooms. Even if participants wanted to be alone in their bedrooms with a partner, care services often have strict regulations about clients having guests in their bedrooms. Paul also perceived the lack of privacy as one of the reasons why he did not have a partner – even to the extent that he felt others were listening to his telephone conversations:

Interviewer: What about boyfriends. Is it hard finding a boyfriend?
Paul: Very hard, very hard for me, very hard.
Interviewer: What do you think makes it hard?
Paul: It’s very difficult to speak at the moment with others listening. They listen to what you say on the phone. It’s impossible [ ] Yeah [they] listen in the room, in the room and listen in.

Although it would appear that Peter and Paul have not been told explicitly by carers that they cannot take boyfriends home with them, the lack of privacy they experience stops them from doing so. However, other participants such as Ray, have been told explicitly by carers that they cannot take boyfriends home with them:

They said to me if I get a boyfriend, they said to me that er, I can’t really take him back to where I live actually. Because they said they don’t want the whole furniture being wrecked or anything being stolen or something like that.

One might question whether Ray’s carers would have the same concerns if he wanted to take a girlfriend home with him.
As stated earlier, the lack of gay role models and gay support networks means that gay men with learning disabilities are often strongly influenced by their carers' attitudes and beliefs about same sex relationships. These can often be far from conducive to the development of a positively-evaluated gay identity (see Hingsberger, 1993; Jones, 1995). This is demonstrated in the following extract from Jonathan who had been reprimanded by care staff for engaging in consensual sexual behaviour in a day centre:

Interviewer: So you got told off for having sex with Derek?
Jonathan: Hm (...) [ ] Yeah. But I don’t do it any more now.
Interviewer: Why is that?
Jonathan: Don’t know, probably got fed up with it.
Interviewer: What made you fed up with it?
Jonathan: Not very clean and nice.
Interviewer: It’s not very clean and nice? Who said that?
Jonathan: The staff[ ] Don’t do it anymore. “If you want to come to the centre you got to be good”. I learnt my lesson now. [ ] Keep out, keep out of those sort of things.

As can be seen from this extract, his carers' comments have led Jonathan to construe his sexual behaviour as something that is “not very clean and nice” and as something that is not “good”. He has consequently stopped having sexual relationships with other men. Although other participants were reprimanded by care staff for engaging in sexual behaviour in care settings, this did not necessarily change their view of themselves or even curb their sexual behaviour. For example:

Ray: I remember once I got this guy behind the settee and the telly was on and there was nobody in the room and we got naked and all that and we were half way down when one of the staff came in and caught us at it. He told us both off.
Interviewer: And what happened because of that?
Ray: Well nothing really and that when he sort of got off and I got told off. They sort of said to me that um, “You know that you’re not supposed to do that in the cottage [the name given to the residential unit in which he lived]” and all that. But I took no notice of them. I still carried on doing it - I just carried on doing it with another guy.

For many of the participants, living in care settings meant having to answer to care staff
on a day-to-day basis. There was also the expectation that participants would live by the rules and regulations of the care services. For Jonathan, this impacted on his ability to access gay venues as there was an expectation he would be home by a certain time:

The only problem in here is that the staff like me back before it gets too late. They go to bed about eleven. Some staff go about ten they do.

Although other participants were expected to comply with carers’ requests and wishes not all did so. For Jack this meant defying carers and doing his own thing:

And then one day I was going out. It was the day they were doing the party. “Jack are you going out on the party? Can you get back here for seven o’clock?” and I went ‘OK seven o’clock - I’ll be here for seven.’ [ ] I was in the pub right and I thought half past five, six o’clock, six fifteen, and then I thought I’ll go to King’s Cross and book into a B&B. [ ] It was not a gay hotel. I did not know no nice discos to go to so I just went dancing here and then the day after I went back to the hospital. They told me off and said “You’re not allowed to go out for the day” and then when it got to about lunch-time I went back into London for the day.

As the above extracts demonstrate, living in a care setting can and does impact on participants’ ability to develop a positively evaluated gay identity. It can also restrict their access to gay venues and opportunities for developing relationships.

Another important factor for the participants in this study was whether they should tell their carers about their sexuality - especially if to do so would be to jeopardise essential relationships. The next section will address the issue of disclosure of gay identity to others.

4.4.11. Disclosure to family and carers

All of the participants in the current study had the experience of disclosing their sexuality to other people, whether this was to family, friends or professionals. Some participants also had the experience of the people they had disclosed to passing this information on to others, often without their express consent. For participants living within care settings where detailed documentation is kept on residents it is no surprise that information about sexuality was shared between carers and between carers and professionals. For example:
Interviewer: How did Janet [care home manager] find out?
Paul: Sarah [member or care staff] must have told, Sarah must have told her. Sarah must have told her the whole thing. [ ] Cause Janet told Sally [member of care staff]. Janet told Sally about it all. And I say nothing, nothing, keep it a secret from everybody. I want to keep it to myself [ ] They must have told the whole group. It’s very embarrassing, it was really embarrassing, it really was.

Unfortunately for Paul, the secret he wants to keep from everyone has become the secret that everyone knows. As Paul highlights, trying to manage private information within a care setting can prove to be an impossible task and can leave the individual feeling vulnerable and embarrassed. For Stuart and Jack, the decision to disclose their sexuality to others was taken out of their hands when information about their sexuality was passed onto professionals or family members. This occurred after they had been discovered engaging in sexual behaviour with other male residents:

Interviewer: Did mum ever know you were gay?
Stuart: No. Yeah. Once I got told off by the hostel staff about ‘NB’ [ ] My friend, I not mention that name, not on the tape. That’s what it is I put him down, kiss him, hug him and then I got told off by the staff and my mum and my dad.

I got told off and they told my social worker. That’s when he found out I was gay. (Jack)

In these extracts it would appear that family and professionals were informed about the participant’s sexual behaviour as it was viewed as problematic rather than a valid, consensual expression of their sexuality. This again reflects the lack of privacy afforded to people living in residential care settings.

Participants who were ‘outed’ by a third party expressed feelings of anger and upset that this had happened. Ray had the experience of a student nurse telling people at his residential home he was gay after he had been to a gay social group to which she also went:

Ray: She [student nurse] sort o f told everybody at the residential home that I was gay. She shouldn’t have told everybody. I was really angry at her and felt like grabbing her and sort of telling her off.
Interviewer: What happened because she told people - Did anything happen to you?
Ray: No it didn't because they didn't believe her. They thought she was telling fibs, like telling lies and I felt really pleased about that.

Ray's obvious relief that people did not believe the student nurse echoes the fear shared by many participants about others finding out they were gay. Fear of disclosure appeared to be linked to the possible consequences that might ensue if others found out. Participants mentioned a number of feared consequences ranging from verbal and physical abuse to rejection by family and friends to even being made homeless. For example:

Interviewer: What would happen if they [care staff] found out?
Stuart: Me in the street. They don't like it.

I won't tell anyone else at college I'm gay because I thought they would um, they wouldn't talk to me any more because I'm gay. (John)

I daren't tell my father, I daren't, oh no, he'd go mad. (Paul)

I don't know. I just thought that they [parents] might have nothing to do with me any more. (Peter)

Maybe Carol [sister] would tell her husband Bryan, and that wouldn't be right cause he likes head butting people and all that. So I thought that if he knew about it he would sort of come straight towards me and start on me. (Ray)

Deciding who to tell and managing the possible consequences of disclosure is a difficult process for any gay man to deal with (see Cramer & Roach, 1988; Herdt & Boxer, 1993; Remafedi, 1987; Robinson, Walters & Skeen, 1989) but for gay men with learning disabilities, there is also the added risk of jeopardising relationships on which they depend for support. As discussed earlier, many of the participants in this study did not have access to a gay support network which might help to mitigate the possible or feared negative consequences of disclosure (see Gluth & Kiselica, 1994). Given these circumstances, participants used other means to protect themselves from feared consequences. One of the most widely used strategies was that of selective disclosure i.e. deciding who to tell and who not to tell. For the majority of men selective disclosure was
employed to protect themselves from the feared negative consequences as in the case of Stuart:

Brigid knows, my sister knows. [ ] Me tell Brigid please don’t tell Mike [his brother]. If Mike
find out me in big trouble with him [ ] If Mike found out, Mike would phone the police. [ ] All my
sisters know about it and I tell Brigid and all the others please don’t tell Mike. If Mike find out
me in double, double, double trouble.

However, Stuart also used selective disclosure as a way of trying to protect his mother,
who was unwell, from any upset which might ensue from a disclosure of his sexuality:

If mum knows about it she would go mental about it. Mum says, “Stuart please don’t fight”.
Mum upset, mum not very well, it’s my fault. Mum turned around and said, “Stuart are you a
poofter?” I said no, not yet.

Despite the feared consequences of disclosure most participants who did choose to tell
their family and carers were met with acceptance and support rather than the feared
consequences:

No, they, they were ok about it. I wasn’t sure if they’d be ok about it [ ] Well they said if that’s
what I want, you know um (...) If that’s what I want to do, um, relax about it don’t worry about it.
(Peter)

However, for some participants, acceptance from family members was a gradual process,
with it taking some time for them fully to come to terms with the disclosure:

Er, she [his sister] copes alright cause she said I’m her brother and she said she’s got to cope with
it. [ ] Cause she said “at the end of the day it’s up to you if you want to be this way”. She didn’t
like it at first but she said she sort of had to accept it. (Ray)

Only two participants reported receiving negative responses following the disclosure of
their sexuality to others. For Jason, this took the form of verbal abuse from his father:

Interviewer: So dad was a bit cross. What did he say or do?
Jason: (...) “I think you’re dirty”.
Interviewer: How did that make you feel?
Jason: Unpleasant.
However it would seem that for Jason, the negative remarks from his father, despite being unpleasant and no doubt hurtful, were countered by support from his mother:

I said I’d like a black man. He [his father] said, “You’re not bringing a black man in this house”. Mum said, “It’s up to him if he wants to bring back a black man he can”.

After disclosing his sexuality to his church, Mark was forced to choose between them and his life as an openly gay man. As he chose to continue being an openly gay man, he faced rejection and ostracism from his church:

I used to be in this ‘Church of Christ’, a newborn Christian and when I left them, after I told them I was gay, they don’t accept me any more. They want me to change. They said I was not nice, not good and all that. [ ] And they say “Oh we know these gay men, they won’t last you long and you know they’re going to hurt you and desert you”.

By choosing to disclose his sexuality to his church, Mark has had to make a difficult decision about two important aspects of his identity i.e. his gay identity and his identity as a christian. Holding strong religious convictions can be difficult to reconcile with a lesbian or gay identity and can have far reaching psychological and social repercussions (see Coyle & Rafelin, 2000; and Sweasey, 1997, for accounts of how gay men have negotiated religious and sexual identity).

Most participants, even those who had disclosed to few people, indicated that they would like to be able to tell others about their sexuality. In terms of identity principles this perhaps reflects the need for authenticity and integrity (Markowe, 1996). For Mark, the motivation to disclose his sexuality to his parents came from this need to be honest and open with them:

Sooner or later it’s got to come out anyway. I can’t keep it all the time in myself. I’ve got to let them know.

The need to disclose sexual identity is a common experience for many gay men and has
been referred to in the literature as an important part of gay identity development (Garnets & Kimmel, 1991). Some researchers have even gone as far as to say that achieving a positively-evaluated gay identity appears to be contingent upon disclosing one’s sexual orientation to significant non-gay others (see McDonald, 1982).

4.4.12. Coping strategies for avoiding/managing identity threat

Although coping strategies for avoiding/managing threats to identity have been referred to and discussed throughout the analysis section, it is important to examine them in a little more detail in order to elucidate how participants are safeguarding identity processes such as self-esteem, continuity, distinctiveness and self-efficacy. All participants in the current study spoke of strategies they had employed to avoid or manage identity threat. Furthermore, these spanned all three of the strategic levels referred to by Breakwell (1986) (i.e. intra-psychic, interpersonal and intergroup).

One of the simplest strategies reported by several participants was that of secrecy i.e. not telling anyone about their sexuality. As Ray put it “I knew straight away that I was gay and I never told anyone or any of that. I just kept it to myself.” In some ways this can be viewed as an avoidance strategy. Although the individual is residing in a threatening position, whilst others are unaware of this, the individual is able to avoid the experience of a direct threat to identity. At best, such a strategy can only work in the short term. As soon as the individual is forced to acknowledge the threat e.g. being openly challenged by others about their sexuality, a more active strategy is needed if threats to identity are to be avoided/managed. For a number of participants this involved simply lying about their sexuality as in the following extract:

They [care staff] said “What’s this about you putting make-up on?” ‘No.’ “Oh yes, you’ve been putting make-up on. What for? Are you gay?” ‘No.’ “Why are you putting make-up on?” ‘Because I’m going to a fancy dress party.’ (Jack)

Such strategies can be described in terms of ‘passing’ or pretending – in this case pretending to be heterosexual. This is highlighted further in the following quotations:
I said I got a girlfriend. (Jack)

Peter: Just all the pretence really
Interviewer: That you have to pretend you mean?
Peter: Yeah.
Interviewer: You pretend you are not a gay man when you are at work?
Peter: Yeah [ ] I just sort of play cool.

Although this strategy helps the individual to avoid threats to identity processes and can even contribute positively to self-esteem (e.g. in Peter’s case by being accepted by a social group he values), this comes at a price. The individual has to live a lie, with the constant fear of possible exposure. In this respect, Breakwell (1986) states, “passing can represent a threat to continuity in its own right” (p 117).

Although it is more usual for gay men to ‘pass’ as heterosexual, Ray adopted the more unusual strategy of ‘passing’ as a woman. This allowed him to receive attention from men without having to be open about his sexuality:

But I’ve had experience of guys cause when I used to grow my hair really long and it used to be down to here [waist] I used to have lots of guys whistling at me, smiling at me and winking at me and um, doing other things like sort of like blowing a trumpet, hooting in their lorries and cars [ ] I used to wear shorts, showing my legs off [ ] It’s probably because I like my shorts really above my legs and long hair and they thought I was a girl.

One can imagine the negative consequences for Ray in these situations if he were exposed as being a man.

Other participants, when exposed to negative reactions about homosexuality, employed the strategy of challenging others’ rights to pronounce judgement on them. Breakwell (1986) views this as part of the ‘re-evaluation of the prospective content of identity’. If an individual accepts the negatively valued social attitudes attached to a particular identity dimension (in this case sexuality), this can impact negatively on self-esteem. However, if the individual is able to resist the social value system, for example, by challenging the right of other people to make judgements about the characteristic, then self-esteem can potentially be safeguarded. This is the strategy adopted by both Paul and Ray:
I can kiss men if I want to; it’s none of her [care home manager] business. It’s my, it’s my choice; I can kiss anybody I like. (Paul)

I don’t care what anybody says at the end of the day, it’s up to me what I sort of do. If I tell them and they don’t like it then I go, ‘Oh it’s not up to you is it?’ I mean if you want to be this way, it’s up to the guys actually if they want to be gay. ‘It’s not up to you at the end of the day.’ (Ray)

At an intergroup level, over half of the participants employed the strategy of group support - in this case being part of a support group for gay men with learning disabilities. Breakwell (1986) identifies this as an important strategy not only for combating isolation and loneliness but also as a way of providing information relevant to coping with the threat. In this respect, the support group helps to create important social and informational networks for its members. For example, Jonathan and Stuart both saw the support group as a place where they could raise issues of personal interest and find out and exchange useful information:

I’d like to bring it up in the men’s group. Talk about that sort of thing. Would you like to talk about that sort of thing Chris, eh? (Jonathan)

That’s, that’s very good. I like it. I’m glad you asked Stuart to the Men’s group to talk about gays, very good, I like it. I need more information myself, more information on different groups on men, on gays. (Stuart)

Paul on the other hand, viewed his support group as a good place to socialise and meet friends:

It’s a men’s group. See all the men, see how they are. Have a drink with them, my friends. Have a chat.

Having found a support group helpful in the past when he was first ‘coming out’ and, given his current lack of gay support networks, John decided to set up his own support group to help both himself and other gay tenants in the organisation in which he lived:

Um, I’m hoping to set up a group for tenants and there is a tenant I’m hoping to work with. [ ] Maybe we could be in the group one week and go out other weeks and so on. We can discuss
issues like coming out and then the next week it will be going to a club. The other weeks will be
um, um, safer sex.

It can be seen that John is also viewing his group as being a place where individuals can
both socialise with each other and share information.

4.4.13. Participants’ feelings in relation to their sexuality

Given the difficulties inherent in developing a positively evaluated gay identity and the
added impact of being a man with learning disabilities, it is surprising that only two
participants spoke of having had ambivalent feelings about their sexuality at some point
in their lives. For Peter, past ambivalence about his sexuality was linked to the belief that
it would have been “easier” for him if he had been a heterosexual man. However,
“chatting to gay friends” and feeling “more relaxed about going to gay pubs” helped him
to develop more positive feelings about his sexuality. Ray also expressed ambivalent
thoughts about his sexuality, believing that things could have been better for him if he
were not gay:

Well sometimes I wish I wasn’t and sometimes I wish that it could have been more better for me
that I wasn’t gay and I could have sort of done something about it [ ] but now that I’m accepting
who I am I don’t mind being like that cause if I’m going to be gay I might as well enjoy it if I can.

However, despite issues such as lack of access to gay venues, poor sense of affiliation
with gay communities and a lack of gay social networks, by far the majority of
participants in the study reported having positive feelings about themselves in relation to
their sexuality. John and Paul described their feelings about being gay men thus:

Fine, happy, be proud of myself. Really enjoy it. (John)

Very, happy, very happy, very pleased. I like it very much [ ] It’s wonderful for me. I like it very
much. [ ] I’m not sad, not sad at all. I like it, I like it. I enjoy it and it’s fun. (Paul)
4.5. Overview

This study has taken an in-depth look at the experiences of ten men with mild learning disabilities who either identify as gay or who are exploring a gay identity. In particular it has explored how these men have constructed, or are in the process of constructing, a gay identity that interacts with and impacts on another salient dimension of their identity, namely their learning disability. All participants in the current study acknowledged both aspects of their identity and were able to articulate something of the difficulties they have encountered when trying to reconcile a gay identity with an identity as a learning-disabled man. Before the substantive issues arising from this study are discussed, it is important to acknowledge the limitations inherent in carrying out this type of research.

The focus of this study was interviews carried out with ten men. As such, it is not possible to claim that their views are representative of all gay men with a learning disability. Although the participants represented a diversity of perspectives, given their broad age range and differences in their living situations, a number of voices are missing from this study. All of the participants in this study had a mild learning disability. As such, they could all be described as possessing reasonably well-developed daily living skills and a certain degree of independence i.e. all were able to travel outside of their homes without the support of a carer. The views of men whose learning disabilities are more severe and who are perhaps more dependent on carers for their day-to-day existence or those who have no or limited verbal communication skills are not represented in this study. To a certain extent, this reflects some of the difficulties in recruiting participants for this study. Methods that might be employed to recruit gay men without learning disabilities such as advertising in the gay press or in gay pubs and clubs were not available (either because the men had no access to the gay press or gay venues or had limited reading abilities). For the most part, the author was reliant on care services and organisations to identify possible participants for the study. This of course, restricted participation to those men who were openly gay within their care services or to those whose sexual behaviour had led their carers to suspect they were gay. This means that men who have not disclosed their sexual identity to carers or professionals or who are not participating in same sex relationships are not represented in this study. The current
study was also carried out in an urban area with a higher concentration of lesbians and
gay men and consequently a wider range of gay venues. Living in such an area may
impact on carers' and professionals' attitudes and beliefs about homosexuality and
subsequently on the attitudes and beliefs of the participants themselves. Therefore, only
tentative conclusions could be drawn from this study about the experiences of gay,
learning disabled men living in rural areas.

Other limitations of this study that need to be borne in mind are the demands that were
made of the participants during the interview process. Most interviews lasted between
one and two hours and, although most participants reported enjoying taking part in the
interview, it was for some a tiring process, both emotionally and physically. For some
participants, it proved difficult to concentrate for the full length of the interview and
frequent breaks were taken. In some cases, interviews needed to be carried out over two
meetings. This had the effect of interrupting the flow of the conversation and
necessitated frequent summarising and recapitulation by the interviewer. Both of these
points impacted to some extent on the richness and detail of the data obtained. As the
majority of the participants were unknown to the author, time was also needed prior to
commencing the interview to develop a rapport, especially given the highly personal and
sensitive nature of the questions. In any future research study it would be beneficial to
meet with participants on a number of occasions prior to the interview in order to
orientate them fully to the nature of the interview and to allow time for a rapport to
develop.

In future research studies, the nature and wording of the interview schedule would also
need to be given further consideration. Although the open-ended nature of the questions
reduced the likelihood of acquiescence, i.e. participants answering in a way they believe
the interviewer wants - a phenomenon known to occur regularly in people with learning
disabilities (Sigelman et al., 1981a, 1981b), it sometimes proved difficult for them to
understand the nature of the question necessitating further explanation and prompting.
By doing this there is a danger that the interviewer is influencing the direction of the
interview too much rather than allowing themes to emerge as the conversation progresses.
This in part reflects the complexity of the interview schedule and highlights the need to
simplify the questions in any further studies.
Taking into account the limitations of the current study and the restrictions placed on the generalisability of its findings, it does highlight some of the issues faced by men with learning disabilities who identify as gay or who are exploring a gay identity for themselves. In many respects the issues raised by the participants in this study are similar to those raised by gay men in the general population, especially in relation to disclosure of sexuality and desire for affiliation. However, unlike most gay men in the general population the men in this study already had to manage the prejudice and stigma that arise from having a learning disability. All participants were aware of the negative societal attitudes directed towards both lesbians and gay men and people with learning disabilities. As with lesbians and gay men from ethnic and cultural minority backgrounds the participants in this study can be seen as a minority within a minority. As such they are exposed to multiple oppressions and threats to identity. However, further levels of discrimination were highlighted in the current study – discrimination from carers and discrimination from the gay community itself. These findings are in accord with those of Davidson-Paine & Corbett (1995) and Thompson (1994).

Identity Process Theory (IPT) (Breakwell 1986, 1996) has proved a useful framework for understanding how the men in this study have constructed and maintained a gay identity; and for understanding how gay identity and learning disabled identity interact. In addition to the four main identity principles outlined by Breakwell (i.e. self esteem, continuity, distinctiveness and self-efficacy) one further identity principle relating to affiliation appeared to be particularly relevant to the men in this study. This resonates with Markowe’s (1996) finding that affiliation was a salient identity principle for her participants in the construction of lesbian identity. IPT has also shed light on how gay men with learning disabilities manage the multiple threats to identity that arise from their double minority status.

The majority of participants in this study spoke of feeling isolated and cut off from gay community contexts. For some, this reflected a lack of knowledge about the location of gay venues. For others, there was a reluctance to enter gay venues alone as they were unsure what to expect or how to behave. All participants, though, expressed the desire to access gay community contexts and acknowledged the importance of having gay
friendships - factors that researchers (e.g. Frable et al., 1997; Schneider, 1991; Weinberg & Williams, 1974) have consistently linked to higher levels of self-esteem and lower levels of psychological distress in gay men. However, living in and being dependent upon care services that fail to attend to the sexuality needs of gay clients means that gay men with learning disabilities can be denied the opportunity and support needed to develop a gay identity within a safe and nurturing environment. So, mindful of this, what can care services do to promote the psychological well being of their gay clients?

As mentioned above, services need to be fully aware of the impact that care staff’s attitudes and beliefs about homosexuality can have on clients who are gay or who are exploring a gay identity. Within a context where homosexuality is at best not discussed (as found by Jones, 1995) and at worst pathologised, clients are not going to feel safe discussing issues pertaining to their sexuality. This is perhaps an issue best addressed through staff training, where an opportunity can be provided for care staff to explore and acknowledge their beliefs about homosexuality and same sex relationships. This may help to foster a non-judgemental and accepting culture within which sexuality can be openly discussed. This may also go some way to mitigate the negative societal attitudes that gay clients may encounter. Such a culture may also enable gay identified care staff to be more open about their own sexuality and in so doing provide much needed role models for gay clients.

Gay identified staff should also be given the full backing of their services, (following appropriate discussions and risk assessments) to support gay clients, whenever possible, in accessing gay community contexts. In services where there are no (openly) gay care workers, gay advocates or befrienders could be recruited to work with gay clients. If this is not possible then clients could be supported in accessing local support groups for people wishing to explore a gay identity. In certain situations, it may be appropriate for heterosexual care staff to accompany gay clients to gay venues. However, in these circumstances, it would be important for care workers to inform themselves fully beforehand about gay ‘culture’ and ‘norms’.

It is also vital for services to balance their duty of care to their clients in terms of ensuring client safety with the clients’ choices and rights in relation to having same sex
relationships. Whilst it is of paramount importance to ensure that clients are not putting themselves at risk, and to ensure they have the necessary skills to understand and to practise safer sex, as well as the skills to negotiate a personally fulfilling and satisfying relationship, they should be supported at every opportunity in developing the relationships of their choice. In so doing, services would be adhering to and implementing the principles set out in both the United Nations Declaration on the Rights of Mentally Retarded Persons (1971) and the Government White Paper, ‘Valuing People’ (2001). ‘Valuing People’ clearly states that services for people with learning disabilities need to adopt a person-centred approach to planning, meaning that planning should start with the individual and not with services. As the White Paper states, “The Government’s objective is to enable people with learning disabilities to have as much choice and control as possible over their lives and the services and support they receive” (p. 4).

This study highlights a number of implications for clinical psychologists working with gay men with learning disabilities. As discussed, the process of gay identity development, especially for those already occupying a stigmatised position can be extremely stressful and may give rise to a range of psychological difficulties. Therefore, within the context of psychological therapy, the issue of gay identity formation and the mechanisms employed for managing/avoiding identity threat may need to be explored and addressed. However, it is also important for clinicians not to presume that sexual identity is at the root of psychological distress among their gay learning disabled clients (Milton & Coyle, 1998).

Clinical psychologists, with their backgrounds in teaching and training, should also take a lead role in the setting up and facilitation of training programmes for care staff. As stated above, one area in need of attention is that of care staff’s attitudes and beliefs about homosexuality. Through training programmes, psychologists can model and encourage a non-judgemental and de-stigmatising approach to gay clients. Given the lack of resources for gay men with learning disabilities psychologists could, perhaps in conjunction with gay voluntary organisations, take the lead in setting up and facilitating support groups aimed specifically at men with learning disabilities who identify as gay or who are exploring a gay identity. This would provide much needed informational and social networks and help to alleviate feelings of isolation. To be able to facilitate such a
group, it would be necessary for psychologists to have a good understanding of the process of gay identity formation and how this impacts on other salient aspects of identity. In this respect, clinical psychology training courses need to devote (more) time to the teaching of lesbian and gay psychology.

Finally, mindful of services’ duty of care to their clients and the sexual vulnerability of people with learning disabilities, psychologists need to be advocating for a thorough assessment of clients’ understanding of sexuality, relationships, and safer sex and their ability to consent to and negotiate sexual relationships. Interventions can then be devised to address deficits in clients’ knowledge and abilities.

Given the dearth of literature in this area, it is of paramount importance that further research is conducted to explore the experiences and needs of this client group and in particular of lesbians with learning disabilities. One issue central to all participants but beyond the scope of this study was participants’ experiences of sexual vulnerability and power imbalance within the context of sexual relationships. It would also be of interest and clinical utility to investigate in more detail care staff’s attitudes and beliefs about gay clients and the role they believe they should play in supporting the gay clients in their care. Within this, it would be important to explore the effect of disclosure of sexuality on the quality of relationships between carers and clients. Finally, it may also be of interest to explore reasons for lesbian and gay communities’ reported non-acceptance of men and women with a learning disability.

To summarise then, services for people with learning disabilities need to be more mindful of the sociosexual needs of their clients. Lesbians and gay men with learning disabilities need to be supported in developing their sexual identities and need to be given supportive access to lesbian and gay community contexts. There is also a responsibility on the part of lesbian and gay communities to face up to their possible non-acceptance of learning disabled men and women and to ensure that supportive and inclusive spaces are created.


Coyle, A., & Rafalin, D. (2000). Jewish gay men’s accounts of negotiating cultural,


APPENDIX ONE

Interview Schedule
INTERVIEW SCHEDULE

Introduction

Introduce the research and the nature and aims of the study. Explain again about confidentiality and the right not to answer questions if so desired. Obtain consent to audio-tape interviews and explain reason for doing this. Answer any outstanding questions. Inform participant that they can ask for a break at any time they like or end the interview if they want to.

Developing Gay Identity and the context in which this was done

Can you tell me about when you first thought you were gay?

Information to elicit and prompts:

How old was the participant?
Where were they living?
Explore what the participant did, if anything, about this e.g. talked to someone, went to gay places?
Did they know of or about any other gay men? If so, what did they know and think about them?
Elicit information on how they felt about the fact they might be gay?

Initial Disclosure and Reactions

Can you remember the first time you told someone you were gay? What was this like?

Information to elicit & prompts

Who was this?
What did they say to this person?
What was this person's reaction e.g. supportive, unsupportive, dismissive?
How did this make the participant feel?
If no one has been told what are the reasons for this? What does the participant think would happen if he told someone?

Subsequent Disclosures

Who now knows that you are gay?

Information to elicit & prompts

Find out if parents/family have been told
If participant lives in a care home do his carers know?
How do people know i.e. did participant tell them directly or did they find out some other way?
What has been helpful/unhelpful about the way people responded and how did this make the
participant feel?
How did the participant want people to react when he told them? (Make links to way participant felt)
If nobody else apart from person mentioned above has been told what are the reasons for this?
What does the participant think would happen if other people knew?

(Possible place for a break in interview)

[If a break has been taken or if this is the start of the second interview recap’ on what the participant has already told you and ask if this is an accurate summary].

Community Networks & Visibility

Do you ever go to gay pubs, clubs or other places where there are other gay men? Can you tell me about this?

Information to elicit & prompts

Find out about the range of places the participant goes to and his experiences of these places (both positive & negative). Does he go alone or with someone? How have other gay non-learning disabled men reacted to him?
How long has he gone to gay pubs/clubs?
How does participant feel going to gay places?
If participant does not go to gay places explore why this is and whether he would like to be able to? What support would he need?

Do you have any friends who are gay? Can you tell me a bit about them?

Information to elicit & prompts

Explore the nature of these relationships and if they are a source of support to the participant.
If participant does not have any gay friends find out if he would like to have. Would it be helpful in any way?

Cultural Stigma/Internalised Homophobia

What sort of things have you heard other people say about gay men? How has this made you feel?

Information to elicit & prompts

Find out about positive and negative comments and the effect this has had on the participant. Has it changed the way they feel about themselves in any way?

How have people treated you when they know you are gay? How did this make you feel?

Information to elicit & prompts

Elicit information on both positive & negative experiences
Check if other gay non-learning disabled men have ever treated the participant in a negative way. Explore whether they have ever been exploited by other gay non-learning disabled men.

**Passing**

Have you ever told people that you are not gay? Can you tell me about any of these times?

*Information to elicit & prompts*

Explore what these situations were and what the participant thought would happen if the person knew he was gay.

*(Possible place for a break in interview)*

[If a break has been taken or if this is the start of the third interview recap’ on what the participant has already told you and ask if this is an accurate summary].

**Positive Self Perceptions**

I would like to talk a little bit now about how it feels being a gay man. Can you tell me generally how it makes you feel?

*Information to elicit & prompts*

Find out about both positive and negative feelings. If necessary give examples of how someone might feel (again both positive & negative examples). Explore whether the participants feelings have changed over time and what might have brought about the change (make links to actual events).

Have you ever wished that you were not gay? *(If yes)* Can you tell me about these times?

*Information to elicit & prompts*

Explore participant’s reasons for this and how he thinks things would be different if he were not gay.

**Learning Disability and Effect on Emotional Well Being**

How have people treated you when they know you have a learning disability? How did this make you feel?

*Information to elicit & prompts*

Elicit information about when and where this was and how it made the participant feel.

Have you ever wished that you did not have a learning disability? Can you tell me about any of these times?
Information to elicit & prompts

Explore what feelings the participant had at these times and how they think things may have been different for them if they did not have a learning disability.

[Depending on participant’s level of comprehension ask]: Do you think that having a learning disability has made it difficult for you to be gay? [If yes], Can you tell me about this?

Information to elicit & prompts

Try to explore whether the participant thinks things would have been different if they did not have a learning disability and how they may have been different.

Reflecting on the Interview Process

Can you tell me what it has been like for you taking part in this interview?

Information to elicit & prompts

Elicit information on the things that the participant has liked and not liked about being interviewed and how it has made him feel.

Thank participant for his help in the study. Ask if there are any further questions he would like to ask or if he thinks there is any other information it would be important for you to know. Repeat assurances about confidentiality and anonymity and explain how he can contact you if he needs to.
APPENDIX TWO

Demographic Information
Demographic Information

[Begin by explaining the following to the participant]

I would like to begin by asking you some questions about yourself such as your age, where you live, what you do, your learning disability and your sexuality. The reason that I would like this information is so that I can show people who read my report that I have spoken to a range of gay men with a learning disability. The information you give me will not be used in any way to identify you and will remain confidential. If you would rather not answer any of the following questions that is absolutely fine.

[The answers to the following questions should be obtained in the context of a conversation with the participant]

1. How old are you?
2a. Where do you live?
2b. Is that a community care home/own home/family home?
2c. How long have you lived there?
2d. Where did you live before that?
2e. Was that a community care home/long stay hospital/family home?
3a. Who do you live with?
3b. Who is in your family?
3c. Which of your family members do you see or speak to?
4a. Do you work? If yes what do you do?
4b. If no, what do you do during the day?
4c. What type of school did you go to (e.g. mainstream or special needs)?
4d. [If this is a mainstream school] Did you leave school with any qualifications?
5a. Would you say that you had a learning disability/difficulty?
5b. If not, does anyone else say you have a learning disability/difficulty?
6a. Do you have a girlfriend or boyfriend at the moment?
6b. How long have you been together?
6c. If you do not have a girlfriend/boyfriend now, have you had one in the past?
6d. How long ago was this?

Thank participant for their cooperation, ask if they have any questions they would like to ask at this stage and then explain about the next part of the interview i.e. talking in more detail about their experiences of being a gay man with learning disabilities.
APPENDIX THREE

Information Sheet for Participants
INFORMATION SHEET FOR PARTICIPANTS

Title of study: The Impact of Gay Identity Formation on the Mental Health of Men with a Learning Disability.

[This will be given to participant to read if they are able to otherwise it will be read to them].

This study aims to look at the type of experiences you have had of being a gay man with a learning disability. In particular it aims to look at how being both a gay man and a man with a learning disability makes you feel.

The information you give me will help professionals who work with people with learning disabilities to think about the sort of help and support they need to give to men who are or think they might be gay.

If you agree to take part in the study I will meet with you for about one and a half hours to talk about what is has been like for you being both a gay man and a man with learning disabilities. I will ask you things about when you first thought you might be gay, who you told and the way people have treated you when they know you are a gay man with a learning disability. We could meet several times if this would be easier.

The interview will be taped recorded and afterwards I will write down what you have told me to help me think about what you have said. I may then write some of the things you have said to me in my study although I will not write your name down in the study so that nobody will know that you have said these things.

Participation in the study is voluntary. This means it is up to you if you want to take part in the study or not and it is absolutely fine if you choose not to. If you choose not to take part in the study this will not affect any future help you may need from the learning disabilities team. The tape of our meeting and the things I write down will only be used by me and another person who is helping me with the study. Nobody else will hear the tape or know which things you have said to me. When the study is finished I will destroy all of the taped interviews.

If you decide to take part in the study but later decide that you do not want to that is absolutely fine. You do not have to tell me why you have changed your mind. If you wanted to talk to me again after we have met we can arrange a time to do this.

If you have any questions at this stage you can telephone me on the number above.

Thank you for your time and help

Christopher Bennett
Chartered Clinical Psychologist
CONSENT FORM

I ____________________(name) have chosen to take part in the study on the impact of gay identity formation on the mental health of men with a learning disability.

I have read (or have had read to me) and understand the information sheet provided. I have been told why the study is being carried out, how long it is likely to take and the type of questions I will be asked. I have been able to ask questions about the study and have understood the answers I was given. I have been given time to decide if I want to take part in the study and agree to talk with Christopher Bennett about what is like for me being a gay man with a learning disability. I agree to our meeting being taped.

I understand that the tape of the meeting and the things that are written down will only be seen by Christopher Bennett and the person helping him with the study. I agree that the things I say can be used in the study as long as nobody knows that I have said these things.

I understand that I can change my mind about taking part in the study at any time and that I do not have to give reasons for this.

Name of participant: .....................................................
(BLOCK CAPITALS)

Signed: ..............................................................

Date: .............................................................

Name of witness: .....................................................
(BLOCK CAPITALS)

Signed: ..............................................................

Date: .............................................................

Name of Investigator: ..................................................
(BLOCK CAPITALS)

Signed: ..............................................................

Date: .............................................................
APPENDIX FIVE

Ethical Approval
Dear Mr Bennett

The impact of gay identity formation on the mental health of men with a learning disability: A double discrimination* (ACE/99/28/Psyd)

I am writing to inform you that the Advisory Committee on Ethics has considered the above protocol and has approved it on the understanding that the Ethics Guidelines are observed and that the following condition is met:-

approval for the study is obtained from the Riverside Ethics Committee and a copy of the letter confirming this is submitted for our records.

The letter of approval relates only to the study specified in your research protocol (ACE/99/28/Psyd). The Committee should be notified of any changes to the proposal, any adverse reactions and if the study is terminated earlier than expected (with reasons). I enclose a copy of the Ethics Guidelines for your information.

Yours sincerely

Helen Schuylerman

Helen Schuylerman (Mrs)
Secretary, University Advisory Committee on Ethics

cc: Professor L J King, Chairman, ACE
    Dr A Coyle, Supervisor, Psychology
    Enc.
Mr Christopher Bennett  
Chartered Clinical Psychologist,  
BKCW Mental Health Trust,  
Services for People with Learning Disabilities,  
34 Galena Road,  
London W6 0LT

Dear Mr Bennett,

RREC 2069 - The Impact of Gay Identity formation on the mental health of men with a Learning Disability: A double discrimination?

I am writing to inform you that the above study has been considered and approved by Chairman’s Action.

Please note the following conditions which form part of this approval:

[1] This approval is for one year only. For projects with an expected duration of more than one year, a letter from the principal investigator will be required in order to further extend consent. This will enable the Committee to maintain a full record of research.

[2] Any changes to the protocol must be notified to the Committee. Such changes may not be implemented without the Committee’s approval.

[3] The Committee should be notified immediately of any serious adverse events that are believed to be study related or if the entire study is terminated prematurely.

[4] You are responsible for consulting with colleagues and/or other groups who may be involved or affected by the research, e.g., extra work for laboratories. Approval by the Committee for your project does not remove your responsibility to negotiate such factors with your colleagues.

Cont/2..
Cont./2. RREC 2069 - The impact of Gay Identity formation on the mental health of men with a Learning Disability: A double discrimination?

[5] You must ensure that nursing and other staff are made aware that research in progress on patients with whom they are concerned has been approved by the Committee.

[6] Pharmacy must be told about any drugs and all drug trials, and must be given the responsibility of receiving and dispensing any trial drug.

[7] The Committee must be advised when a project is concluded and should be sent one copy of any publication arising from your study, or a summary if there is to be no publication.

May I take this opportunity to wish you well in your research. If any doubts or problems of an unexpected nature arise, please feel free to contact me at any time.

Yours sincerely

C G Mackworth-Young MA MD FRCP
Chairman - RREC

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