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Submitted for the Doctorate of Psychology (PsychD) in Clinical Psychology

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EATING PATTERNS IN A POPULATION OF PEOPLE WITH LEARNING DISABILITIES: TYPES, PREVALENCE AND ASSOCIATED POPULATION CHARACTERISTICS

Volume One

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SECTION ONE

ACADEMIC DOSSIER
LONG TERM DISABILITIES ESSAY

Describe The Issues In Working With Someone With Long Term Mental Health Problems And Discuss Which Psychological Approaches May Be Useful In Helping Them

December 1996

Year 1
The definition of chronic mental illness (CMI) has changed over the last 10-15 years. Before deinstitutionalisation the criterion for chronicity was primarily based on frequency and duration of hospital admissions (Bachrach, 1988). However, with the advent of Care in the Community and the subsequent closure of many large long stay psychiatric hospitals, the current criterion for defining CMI relates to duration and diagnosis of symptoms and level of disability. Duration is defined by the time of symptom onset and prolonged or repeated hospitalisation. Diagnosis is made on the basis of psychiatric symptoms such as depressed mood, hallucinations or delusions. Secondary disability is seen to lead to considerable financial, social, vocational and personal handicaps. As a result, patients with CMI are one of the most needy and disadvantaged groups of society (Shadish et al, 1989).

The specific attributes of CMI create a number of issues and implications in planning care and rehabilitation services. These include the primary effects of illness symptoms, long term use of medication and chance of relapse, diversity of care settings encountered and secondary impairments of long term illness. For the psychologist, rehabilitation has become a specialised and multi-skilled area. A number of psychosocial approaches and models have been adapted to affect intervention and improve overall patient functioning. This paper will review the main issues in working with CMI and psychosocial approaches that have been successfully implemented.

Issues in CMI

Variability of Diagnoses

Clinicians are aware that patients with chronic psychiatric difficulties represent a complex and heterogeneous group. Chronically disabled psychiatric patients exhibit a wide range of symptomatology and levels of handicap. Diagnostically, schizophrenia is the most frequent condition encountered but other diagnoses include chronic anxiety related conditions, long standing personality or conduct disorders, and behavioural problems relating to moderate mental handicap, neurological or degenerative conditions. All diagnoses bring a varying severity and collection of symptoms for health workers to manage.
Medication and Psychotic Symptomatology

Since the introduction of anti-psychotic drugs in the mid 1950's, the long term management of illness symptoms has improved and allowed many patients to function in community care settings as opposed to psychiatric institutions. The use of medication plays a vital role in CMI today and has allowed rehabilitation services to develop management programmes concentrating on the secondary impairments encountered by patients with CMI. However, although many people with psychosis receive some benefit from prescribed medication, according to Liberman (1994), a minority of patients (15%) have symptoms that are resistant to biochemical interventions and a majority still experience some continuing positive psychotic symptoms (e.g.: Curson et al, 1985). Positive symptoms often involve major disturbances in thought, feeling and behaviour. Patients will often exhibit problems with altered perception, affective disturbance and behavioural difficulties. Altered perception involves experience of auditory or occasionally visual hallucinations and delusional beliefs (paranoid, grandiose, depressive and/or explanatory). Emotional disturbance can include severe anxiety, despair, loneliness and feeling of unworthiness. Surveys reveal that severe symptoms of depression and anxiety are very common amongst people with CMI. Up to 65% of patients who have been diagnosed as schizophrenic may experience a depressive episode over a one to three year period (Johnson, 1981). Panic and anxiety symptoms occur in around 60% of people with chronic psychosis (Moorey and Soni, 1994). Studies have shown that symptoms of emotional disturbance may be predictive of risk of relapse (e.g.: Johnson, 1988) and risk of suicide (e.g.: Caldwell and Gottesman, 1990). This suggests that affective symptoms are equal if not of greater importance to psychotic presentations in CMI.

Psychotic patients also exhibit distressing bizarre or inappropriate. In recent years a minority of long term schizophrenic patients have received 'bad press' relating to episodes of violent behaviour. More commonly observed are less serious behaviours, which may include inappropriate dress or speech. According to Corrigan et al (1990) patients with CMI frequently have difficulty picking up social cues and judging what is their required behaviour in certain situations.
An important issue for consideration when working with CMI is that psychotic symptoms do not only differ considerably between individuals with similar diagnoses but can also vary enormously within an individual over time.

**Cognitive Impairments**

Patients with CMI frequently display difficulties with cognitive processing and attentional deficits. Planning and executing tasks become difficult in the face of cognitive confusion. Often patients exhibit a very short attention span and poor concentration, which proves detrimental to carrying out even the simplest of tasks. They can often be labelled by carers as lazy and uncommitted.

**Motivational Difficulties**

Problems of low motivation can result from disturbances in cognitive functioning. Often patients who can not plan activities or make decisions appear to others to be unmotivated (Perkins and Dilks, 1992). A lack of insight into their condition can also result in a reluctance to take up various forms of psychiatric services.

**Lack of Insight**

Patients with CMI often lack insight into their condition, which has implications in how best to manage them. Some may explain their difficulties based on their delusional belief system; others may adopt physical explanations. Others may consider that they have no problems at all. The way patients construe their difficulties is important when attempting to plan services that meet their needs. A great deal of intuition may be needed on the part of the team to find ways for treatment to be acceptable for each individual patient.

**Compliance**

Traditionally, patients with CMI have exhibited poor compliance to medication regimens and psychosocial rehabilitation programmes (Corrigan et al, 1990). Poor compliance is a significant factor in the revolving door syndrome where patients have multiple rehospitalisations for relapse of symptomatology (Vaccaro et al, 1992). According to Corrigan compliance is effected by treatment techniques, patient characteristics, care settings and the treatment delivery service.
Relapse

Even if patients comply with medication scripts, mental states in psychosis fluctuate over time. Patients with CMI are vulnerable to everyday stresses which most people can cope with adequately (Amberlas, 1987). There may be times when an individual is better able to cope depending on social circumstances. However CMI patients are at high risk of relapse, especially if they live in the community and are exposed to varying social adversities (Kuipers and Bebbington, 1990). Although medication is a protective factor, Remington and Adams (1994) report that 25% of psychotic patients may still relapse over a two year period and between 40% and 60% may relapse over a five year period.

Neuroleptic Side Effects

Long term use of anti-psychotic medication can produce a number of distressing and permanent side effects in patients. These may involve changes in levels of behavioural and cognitive functioning (Nuechterlein et al, 1992) and have implications for care planning. Traditional neuroleptics have been known to produce restlessness, apathy, anhedonia, dysphoria and parkinsonism. Long term medication can worsen patient ability to attend to tasks and can impair vocational rehabilitation (Hogarty et al, 1988).

Secondary Impairments

In addition to the intrinsic effects of CMI (symptoms), patients experience a wide range of secondary impairments that disrupt their overall level of functioning. Surveys have suggested that up to 60% of patients with schizophrenic syndromes and significant minorities of people with other psychotic disorders, may show signs of moderate to severe social disability (e.g.: Johnstone et al, 1991). These problems can include an inability to function at work and subsequent unemployment, diminished social networks (Sokolovsky et al, 1978), and social stigma and rejection by family and significant others (Leff and Vaughn, 1985). As a result, many of these patients are unable to live independent lives and rely on relatives, social or mental health services to meet their needs for daily living. Dependency on care services appears more pronounced in patients who have spent many years in psychiatric institutions where little opportunity may have been provided for practising daily living skills such as
independent dressing, cooking, shopping or managing financial affairs. Many of the newer patients with CMI who have never been institutionalised, do manage to live in the community but still manifest clinical, social and vocational problems.

Because medication has become more effective for long term management of illness symptoms, residual impairments and handicaps have become a greater focus for many rehabilitation programs and psychological approaches to CMI. According to Wing (1983) the presence of social disability is likely to depend on at least four factors; chronic impairments (cognitive deficits); illness symptoms; adverse social circumstances (stress, stigma, rejection) and attitudes to self (emotional disturbance). The complex interaction of these factors suggest significant differences in the nature of social disability and implies the need for a range of approaches tailored to the individual patient (Fowler et al, 1995).

*Care Settings and Care Staff*

The quality of the physical environment in which patients live and carers attitudes towards the provision of services can markedly hinder or facilitate rehabilitation (Holahan, 1976; Lavender and Watts, 1995). Patients with CMI can be living in a variety of setting such as long term hospital wards, residential group homes, warded flats or family homes. Each environment brings differing implications for rehabilitation services and indicates the need for a great deal of flexibility and negotiation.

It seems vital to consider the physical and psychological structure of care (Lavender, 1985) when planning and implementing rehabilitation programmes. Institutions will often follow certain strategies and policies to facilitate overall care procedures. A number of research studies have identified factors that have influenced rehabilitation practice (e.g. Lavender, 1987), including; degree of patient autonomy; the degree of patient personalisation vs. depersonalisation and degree of social integration vs. segregation.

For patients living at home, the family is considered to be an important force, which can affect the course of CMI. Research has suggested that families may be a causative agent for mental illness and may be a powerful maintaining influence. Family
relationships can therefore have a significant effect on patients long term rehabilitation and illness prognosis.

In many cases the success of a programme will depend on the co-operation and good working alliance with ward staff, keyworkers or family members. For example, family attitudes and expectations have been shown to have a relationship to the long term outcome of rehabilitation. Joint decision making at the planning stages and continuing support can often enhance morale, cohesiveness and effectiveness of rehabilitation programmes (Edkawi and Conning, 1993).

**Psychosocial Approaches to CMI**

Before deinstitutionalisation, the main role of the psychologist in hospital settings was to perform research, assessments and interventions under the supervision of physicians (Smith et al, 1993). The Care in the Community movement resulted in the decentralisation of health care services and many patients faced providing for their own needs. Broad changes were required in the treatment of people with CMI. These changes involved an enhanced role for the psychologist in rehabilitation teams and an increased use of psychological approaches to long term care. These approaches can be categorised under five main headings; 1) Assessment 2) Psychological treatment of CMI symptoms 3) Relapse prevention 4) Psychological management of secondary impairments and 5) Indirect interventions with families and care staff.

**Assessment**

The issue of assessment is particularly important in this area because of the changing nature of patients’ symptoms, level of social disability and response to rehabilitation interventions. According to Conning (1991), Clinical Psychologists are well suited to carry out numerous assessment procedures due to having an extensive training in scientific methodology and ability to integrate information into theoretical models for guiding intervention.

Initial psychological assessment not only aids symptom diagnosis but also helps identify precipitating and maintaining factors of maladaptive behaviour and low level of
social and psychological functioning. This will be important information for guiding interventions. For example, according to the vulnerability model of CMI, patients are likely to present with higher levels of psychotic symptoms when exposed to stressful environments (Smith et al, 1993). This may include families that express high levels of emotion and critical comment or institutions that discourage social integration and personalisation. Functional assessment proves important for identifying salient antecedents and consequences for behaviour that can be targeted in treatment (Hall et al, 1989)

Regular assessment for patients with CMI is valuable for evaluating patient compliance to and effectiveness of medical and psychological interventions. Intervention outcome is normally measured by changes in psychotic symptoms, behaviour, emotional and social functioning. Regular psychological assessment of patient with CMI has also been important in the prevention of psychotic relapse (e.g.: Subotnik and Neurochterlein, 1988).

Assessment of care environments and attitudes of carers is also important as these factors often influence the course of CMI.

The recognition of the value of psychological assessment in CMI rehabilitation has led to the development of a number of standard tools. The expanded version of the Brief Psychiatric Rating Scale (BPRS) (Overall and Goreham, 1988) was designed to detect and monitor psychiatric symptomatology and emotional and functional effects of CMI. Behavioural observations such as time sampling has proved to be sensitive indicators for evaluating response to medication and other interventions. Lavender (1984) developed an assessment tool, Model Standards Questionnaire, to measure the quality of care in psychiatric hospitals. This has been subsequently extended to include assessment in a wider variety of mental health settings (e.g.: Clifford et al, 1989)
Psychological Approaches to the Treatment of CMI Symptoms

Numerous developments have been made in psychological approaches to the treatment of chronic psychotic symptoms. These approaches have in the main been cognitive or behavioural in orientation.

Approaches to the management of persistent auditory hallucinations have included principles of behavioural punishment, time out, desensitisation, distraction and cognitive restructuring to name but a few. Outcome studies have produced encouraging results, indicating some reduction in the frequency, duration and intensity of hallucinations. However, the degree of change has proved variable cross time and treatment settings and most of the studies have suffered from methodological problems. Despite this, psychology has contributed significantly to theoretical models of hallucinations (e.g. Birchwood et al, 1988) and subsequent successful interventions. Particular techniques such as stress management, thought stopping, cognitive distraction and use of ear plugs have proved successful in combination.

Psychological techniques have also proved successful in the treatment of delusions. Operant procedures have focused on modification of delusional speech using social reinforcers, positive feedback and token economies (e.g.: Wincze t al, 1972). More recently cognitive approaches have focused on modification of beliefs using a challenging non confrontational style of therapy (Milton et al, 1978) and reality testing (Chadwick and Lowe, 1990). Both approaches have exhibited a reduction in symptomatology. However, operant procedures may exhibit less face validity than cognitive approaches as they are only noted to succeed in reducing the reporting of delusional beliefs rather than the experience of them.

It seems important not to neglect the importance of affective disturbance on general level of patient functioning and chance of psychotic relapse. Regular assessment and implementation of various psychological approaches can help identify and manage emotional disturbance and can be integrated with other procedures for dealing with psychotic symptoms. For example, adaptations of cognitive therapy for depression (Beck, 1979), schema focused therapy for personality disorders (Young, 1990) and
stress management skills for anxiety have proved to be useful for patients with CMI (Fowler et al 1995).

Psychological approaches have also been used to intervene with patient who exhibit cognitive impairments. Direct interventions have been used to improve attention, memory, processing, and planning skills, particularly for psychotic individuals. Cognitive-behavioural approaches have focused on training in self monitoring, cognitive self regulation, problem solving and reality testing. Meichenbaum and Cameron (1973) applied self instructional training to enhance patients attentional skills with mixed results. More recently approaches have focused on training patients in compensatory strategies and coping mechanisms. Brenner et al (1990) has successfully implemented an integrated approach involving cognitive, communication and social skills training.

Traditionally behavioural approaches have been used to help modify patients inappropriate or challenging behaviour. In large institutions Token Economies were popular programmes based on operant reinforcement for shaping desirable behaviours. Since the introduction of community care, behaviour programmes still continue to be important but tend to be implemented as individualised programmes or in small group situations.

Relapse Prevention

Contemporary supportive, psychoeducational and cognitive-behavioural approaches have been used to teach patients and carers how to identify and act upon early signs of relapse. These signs usually involve affective changes and mild psychotic symptoms. Strategies that that been implemented involve; providing information about the nature of CMI and effect of medication; monitoring symptoms and early warning signs; stress management (in relation to the vulnerability model of psychosis) and teaching patients to seek help from psychiatric or rehabilitation services (Fowler et al, 1995)
Management of Secondary Impairments

With the relatively successful use of medication to control psychotic symptoms, psychological approaches to rehabilitation have concentrated on helping patients with disabilities and handicaps that are secondary to their illness.

Social disabilities found in patients with CMI are assumed to reflect the combined influences of psychotic symptoms, lack of environmental stimulation and loss of skills due to prolonged misuse (Liberman et al, 1989). Social skills training (SST) has proved effective in enhancing interpersonal relationships, problem solving skills, daily living skills, vocational skills and prevention of symptom relapse (Liberman, 1992). However, SST has been found to have low generalisation effects and durability for patients with CMI. Psychologists have found that successful interventions must occur at regular intervals in setting where skills are likely to be used and socially reinforced (Ekdawi and Conning, 1993).

Indirect Interventions

Clinicians have identified that successful rehabilitation of patients with CMI largely depends on working indirectly with relatives and care staff. Not only do carers play an important role in implementing programmes but also influence overall patient prognosis. Families are often left to carry the burden of care for their ill relative which can be an enormous source of stress and anxiety. Environmental stress and familial expression of high levels of emotion have been linked to subsequent rates of relapse in chronic psychotic patients (Leff and Vaughn, 1985). As a result, a number of psychological approaches for family interventions have been developed with varying degrees of success. Cognitive behavioural and counselling orientations have proved more effective than psychodynamically orientation programmes. Leff et al (1994) emphasises some important factors for successful family intervention including; a good working alliance between health professionals and carers; providing education regarding the nature of CMI; improving communication and problem solving skills; reducing levels of expressed emotion; expanding social networks and lowering relatives expectations regarding the patients level of functioning and prognosis.
Outcome studies have shown relative improvements in families level of distress and ability to cope and patients rate of psychotic relapse (Leiberman et al, 1994). Similar considerations are needed for working effectively alongside care staff in psychiatric wards, hostels and group homes.

**Conclusions**

This paper has concentrated on the issues in working with patients with CMI and how psychological procedures have been subsequently applied. It is beyond the scope of this paper to examine in detail the full extent of the role of psychology in CMI rehabilitation. Other psychological approaches include; the use of research to enhance therapeutic theory, practice and service development; the use of teaching forums for the transfer of therapeutic skills to carers and other professionals; the use of skills to enhance patient compliance.

There are undoubtedly a number of issues in working with people with CMI and these appear to have driven development of policy and provision in rehabilitation services. The notable outcome is the invaluable role of a psychologist and use of applied psychological principles within a core rehabilitation team. The chronicity, severity and fluctuating mental states of patients with CMI emphasise the continuing need to focus on long term management rather than cure. Service providers are also aware of the efficacy of flexible individualised care planning and the vital inclusion of relatives and care staff.
References


ADULT MENTAL HEALTH ESSAY

Discuss The Efficacy Of Cognitive-Behavioural Therapy For The Treatment Of Bulimia Nervosa

March 1997

Year 1
Introduction

Numerous evaluation studies for the treatment of Bulimia Nervosa (BN) have been published over the last decade providing compelling evidence that CBT is the first line treatment of choice. However, the diversity of research methodology employed, places limits on the reliability of comparing results across studies. Also not all BN sufferers respond well to CBT.

This essay will provide a brief account of outcome studies regarding the efficacy of CBT for treating Bulimia along with the methodological considerations for comparing such studies. Current limitations for using CBT will be discussed in relation to employing a hierarchical and integrative system of treatment.

Theoretical Model

One justification for using standardised CBT approaches to treat BN is based in the development of aetiological and maintenance models emphasising the interplay between behavioural and cognitive factors. These factors are also reflected in the DSM-IV diagnostic criteria for BN, which includes classification of salient behaviours such as binge eating and purging and cognitive distortions in relation to body shape and weight. Wilson's (1989) cognitive-social learning model of BN provides a valuable framework for understanding and assessing bulimic problems. He proposes that dysfunctional attitudes about body weight and shape and fear of weight gain leads to restrained eating patterns. Rigid dietary standards build up biologically and psychologically driven food cravings, which precipitate episodes of bingeing. Binges are thought to be influenced by psychological states such as stress and negative mood. Loss of control over eating is followed by heightened anxiety. This is subsequently reduced through purging behaviours and increased dietary restraint thus completing the "loop" of symptom maintenance. Evidence for this formulation comes partly from studies using the Stroop Colour Naming paradigm (e.g.: Wilson et al, 1989) supporting the notion that cognitive factors play an important role in the maintenance of the disorder. Other sources of support come from studies emphasising the usefulness of the CBT model in generating effective treatment strategies.
The CBT formulation as proposed by Wilson has its limitations. It appears that the model is a clearer explanation for the maintenance of BN symptoms than for the aetiology of the disorder. Many normal weight dieters and sufferers of anorexia nervosa do not develop bulimic episodes. As Wilson rightfully points out, other variables may play important roles in determining who initially develops bulimia. These may include genetics, family dynamics, personality and interpersonal factors. These may be important considerations for treating BN sufferers who do not respond to CBT interventions.

Global Outcome Studies

A number of meta-analyses of outcome studies of CBT for BN have yielded comparable figures for reductions in bingeing and purging after treatment. Garner et al (1987) summarised 19 studies evaluating the outcome of CBT and found a mean reduction in bingeing of 79% with a 45% remission rate at follow up and a reduction in vomiting of 84% with 45% remission rate. Similar results were found in subsequent studies (Craighead and Agras, 1991; Wilson, 1995). This is in contrast to no change or worsening of symptoms in subjects assigned to waiting list or no treatment control groups. Studies have also consistently shown that CBT can significantly reduce dietary restraint (Fairburn et al, 1991; Garner et al, 1991, Wilson et al, 1991), and increase the amount of food eaten between bulimic episodes (Rossiter et al, 1988). It should be noted here that this method of summarising data has problems. Researchers attempt to blend studies with often very different designs and treatment methods. These limitations will be considered in more detail in a later section.

CBT vs. Other Treatments

Pharmacology

A number of different research designs have been adopted to explore the efficacy of CBT compared to antidepressant drug therapy. In studies comparing CBT with Medication, CBT has been found to be significantly more effective at post-treatment, for reducing bingeing and purging compared to desipramine (Agras et al, 1992) and Fluoxetine (Goldbloom et al, 1995).
Studies comparing CBT plus medication with medication alone found that the combined treatment was most effective for reducing bingeing and purging. (e.g.: Leitenberg et al, 1994; Agras et al, 1992; Mitchell et al, 1990; Walsh et al, 1995) Studies comparing CBT plus medication with CBT alone found that antidepressant treatment did not add to the effectiveness of CBT in terms of normalised eating patterns, however it did appear to lead to greater reductions in measures of depression and anxiety. (e.g.: Agras et al, 1992).

In general, it appears that CBT is superior to medication alone and that a combined treatment is significantly better than just the use of antidepressants. CBT may be a more acceptable form of therapy to patients (Wilson, 1996) resulting in fewer drop out rates during treatment. However, to date there have been no follow up studies exploring the long term effects of medication except for Agras et al (1994) who found that desipramine produced lasting effects even after withdrawal.

**CBT vs. Non Behavioural Psychotherapies**

*a) Reductions in Bingeing and Purging.*

Most research studies have found CBT to be as effective as or superior to almost all other forms of psychotherapy in the treatment of BN using bingeing and purging as the measures of outcome. CBT has been shown to be more effective than supportive psychotherapy (Agras et al, 1989), supportive-expressive psychotherapy (Garner et al, 1993), and stress management (Laessle et al, 1991).

Other studies have found fewer differences. Freeman et al (1988) compared CBT, behavioural therapy, psychotherapy and a waiting list control and found all three treatments were equally effective and superior to the control group. Kirkley et al (1985) found that a group receiving CBT had significant reductions in bingeing and vomiting compared with a group receiving non-directive therapy, however the differences disappeared at 3 months follow up, and CBT did not show superiority for treating symptoms of depression. Fairburn et al (1986) found no differences in bingeing and vomiting between CBT and short-term psychotherapy at post treatment or at 1 year follow up. However, the group receiving CBT showed significantly greater changes in depression, anxiety, self-esteem and assertiveness compared to the
psychotherapy group. Olmstead et al (1991) compared CBT with an educational group treatment and found that on a number of outcome indices, the educational treatment was equally as effective for the healthiest of patients. Fairburn found the most recent anomaly in evidence for the superiority of CBT, in his group of studies at Oxford (Fairburn et al, 1991, 1993, 1995). He compared CBT with interpersonal psychotherapy (IPT). At post-treatment, both treatments were equally as effective at reducing binge eating but CBT was superior in its effects on purging, dietary restraint, attitudes to shape and weight. However, at 1 year follow up, IPT continued to show improvements and was as successful as CBT on all measures. This outcome was also found 6 years post treatment. To date IPT is the only treatment, which at follow up has shown the same breadth of effects as CBT for treating BN.

b) Changes in Attitudes to Shape and Weight

Central to the cognitive-behavioural view of BN is the presence of dysfunctional attitudes toward shape and weight. Outcome studies for CBT have not only aimed to evaluate the effectiveness of the treatment to reduce bingeing and purging but also recognise the importance of measuring changes in patients specific pathology.

Different studies have utilised different instruments for measuring attitudes to weight and shape. A number of studies have employed the Eating Attitudes Test (EAT) and produced substantial variance in results of treatment efficacy. Although many studies indicate significant reductions in EAT scores with CBT, post-treatment means still appear to reside in the symptomatic range (Schneider and Agras, 1985, Dixon and Kiecolt Glaser, 1984). However, other studies have found that EAT scores continue to decline somewhat at treatment follow up, suggesting either delayed effects of CBT treatment or direct effects of reduced bingeing and purging behaviour. A causal link between bingeing purging and attitude changes is yet to be established. Ordman and Kirschenbaum (1985) found no correlation between bingeing and vomiting and EAT scores, whereas Connors et al (1984) found that improvements on several sub-scales were significantly correlated with reduced bingeing and vomiting.

Other studies have used different measures of attitudes (Restraint scale, Eating Disorders Inventory (EDI)) or a combination of methods. Garner et al (1993) used the
EDI and EAT to measure concerns regarding weight, body shape and eating in a study comparing CBT with supportive-expressive therapy. They found that at post-treatment CBT led to significantly greater improvements on sub-scales measuring concerns for shape. However, no long term follow-up data was evaluated in this study. Thackwray et al (1993) used the EDI to measure attitudes in a study comparing the effectiveness of CBT, behavioural therapy (BT) and a non-specific monitoring therapy (NSMT) group. They found that both the CBT and BT groups exhibited significant reductions in dysfunctional attitudes from pre to post treatment and follow up and these were significantly different from the NSMT group. However there were no significant differences in effects between CBT and BT at follow up.

Fairburn and colleagues recognised the methodological problems associated with self-report measures such as the EAT and EDI and therefore developed the Eating Disorders Examination (EDE), a semi-structured interview schedule which could elicit qualitative information about BN symptomatology and specific attitudes. Using the EDE, Fairburn et al (1995) reported that scores on the sub-scales measuring Shape Concern and Weight Concern were markedly decreased in patients receiving CBT, BT and IPT from pre-treatment to follow up. However, the authors did not report on the specific differences between the three treatment groups with regards to attitude changes.

The effects of CBT on attitudes have not always been clear from past outcome studies. One difficulty is the varied use of different forms of measurement and treatment designs. In general, it appears that CBT has long-lasting and durable effects on specific BN psychopathology compared to other forms of treatment. However, it is unclear whether these effects are related to associated reductions in bingeing and purging behaviour.

c) Changes in co-morbid symptomatology

Some studies have attempted to measure symptom areas beyond those specific to BN. The most consistently assessed area is depression and general findings show that treatment is followed by significant reductions in depression which are maintained over time. However, conflicting results have been produced regarding the superiority of
CBT. Kirkley et al (1985) found no post-treatment differences in depression between group CBT and non-directive psychotherapy. Thackwray et al (1993) found no significant differences in depression between CBT and BT post-treatment and at follow up. Cooper and Steere (1995) found no differences at post-treatment between CBT and ERP but found that at follow up, ERP showed deterioration whereas the CBT group maintained treatment gains. Both Fairburn et al (1986) and Garner et al (1993) found better post-treatment effects for CBT on depression compared to short term psychotherapy and supportive -expressive therapy respectively. Conflicting results have also been produced in relation to changes in anxiety (Wilson et al, 1986; Schneider and Agras, 1985). Other studies have found general post-treatment changes in assertiveness (Connors et al, 1984), self esteem and personality characteristics (Garner et al, 1993).

Generally it appears that changes in specific symptoms of BN are accompanied by changes in non specific psychopathology, however it has yet to be established whether there are any causal links between the two. There also appears to be a lack of research on factors such as changes in family structure or social adjustment.

Mechanisms for Therapeutic Change

There seems little doubt about the efficacy of CBT for the treatment of bulimia. However, as CBT is a combination of cognitive and behavioural techniques, researchers have been interested to identify the most effective elements. This is also important for testing the prevailing theoretical models of BN.

Behavioural interventions are based on the hypothesis that purging is maintained by the reduction of anxiety generated from the fear of weight gain subsequent to binge eating. Environmental antecedents and consequences are thought to control the binge-purge cycle. Exposure - response prevention (ERP) was developed as a technique for breaking the behavioural cycle by preventing or delaying purging following a binge. At face value, this model does not account for the dysfunctional beliefs concerning weight and shape that are characteristic of patients with BN and which may be critical in the aetiology and maintenance of the disorder. (Garner, 1987). Cognitive behavioural interventions emphasise the interdependence of the bulimic persons' beliefs and
behavioural patterns and attempts to modify attitudes as well as reduce bingeing and purging.

A number of "dismantling" studies comparing cognitive and behavioural techniques have been performed to try and identify which elements of CBT are effective in the treatment of BN. However, results have been somewhat inconclusive. Early studies found that ERP may have critical effects in the treatment of BN (Wilson et al, 1986). However others such as Agras et al (1989) found that ERP did not enhance the efficacy of CB intervention. Cooper and Steere (1995) conducted a study to compare CBT without any ERP procedures with treatment using ERP. They found that at post-treatment, both forms of therapy were successful in outcome for specific and non specific psychopathology. However at one year follow up the CBT treatment maintained improvements but the ERP group relapsed. They concluded that this provided support for the cognitive model of maintenance for BN. More recent studies have compared the effectiveness of CBT treatment with behavioural therapies using techniques other than ERP, such as stimulus control and behavioural instructions. Freeman et al (1988) found that in their study, non ERP behavioural therapy was as effective as CBT in reducing binge eating and so concluded that the use of cognitive techniques were unnecessary. However, as pointed out by Wilson and Fairburn (1993), this study failed to measure attitude change (an essential feature of the CB model) and also failed to provide any follow up data of longer lasting effects of treatment. In one of the most methodologically sound studies, Fairburn et al (1991) found that CBT was more effective at reducing cognitive distortions compared to a non ERP behavioural treatment at post-treatment and 1 and 6 year follow up (Fairburn et al, 1993, 1995). They also found that the drop out rate for the behavioural treatment was substantially higher than the CBT group because of poor treatment response. Thackwray et al (1993) found that at post-treatment BT and CBT were equally as effective in reducing bingeing and purging but at 6 months follow up, the CBT group had greater maintenance of effect. The BT and CBT groups showed equal effectiveness for reducing dysfunctional attitudes as measured by the EDI. This is a surprising finding considering that the BT intervention was not focused specifically on attitude change, unlike the CB treatment. The CBT group showed significantly greater
effects on levels of depression at follow up but it was unclear whether it might have related to changes in binge-purge behaviour.

There are problems with comparison studies using cognitive vs. behavioural procedures to evaluate the contribution of cognitive processes in therapeutic change. This is because according to social cognitive theory (Bandura, 1986), performance based techniques produce change mediated by cognitive processes. That is, BT can indirectly modify cognitions. This may explain why in many outcome studies, BT has shown broad treatment effects for BN. However, from the review of outcome studies it would appear that these effects are seemingly short lived compared to interventions involving direct and focused cognitive modification.

**Methodological Considerations**

It is beyond the scope of this essay to detail the problems of comparing outcome studies in this area. Briefly, the variation in study designs and methodology calls for caution in comparing treatment results.

Before Fairburn and colleagues introduced a standardised treatment manual for BN, global outcome studies using CBT varied in the emphasis and structure of therapeutic techniques. Some studies detail the specific use of cognitive restructuring in the CBT package, whereas others use a variety of cognitive and behavioural methods. This may reflect variance in relation to the theoretical framework on which CB interventions were based and the differing emphasis placed on the interplay between cognitive and behavioural components.

Studies have also employed different treatment modalities; group vs. individual CBT. Freeman et al (1985) concluded that group and individual CB interventions were equally as effective in the treatment of BN, but group treatment exhibited higher drop out rates. Garner et al (1987) argue that the majority of studies using group CBT recruit subjects through advertising whereas studies using individual CBT normally recruit subjects through clinical referral. This may reflect differences in the severity of the disorder between these two populations and would therefore suggest that group work might be more effective with less disturbed patients. It would appear that to date
no studies have focused directly in investigating this hypothesis. Differences across studies in the methods of subject recruitment limits the comparability of results and may also account for the large variations found in subjects demographic characteristics.

Studies have differed in emphasis and measurement of treatment outcome. Most studies have focused on the assessment of pre and post treatment episodes of bingeing and purging, relying on a variety of self report measures. More recently investigators have realised the importance of using broader assessments especially in relation to attitudes about weight and shape and general psychopathology. However, studies have again employed a variety of assessment tools to do this, which limits comparability and may account for equivocal findings.

Other methodological differences between studies include variation in the duration and frequency of treatment, variation in the length and conduct of follow up procedures (Range 3 months - 6 years), differences in the number and experiences of therapists used and differences in criteria used for the diagnosis of BN.

Conclusions

CBT is an effective treatment for BN but not all patients respond well to it. Approximately 50% of patients respond well and of the rest, some have a partial response and others do not respond at all (Wilson, 1996). In the light of this, it appears that more studies need to investigate predictor variables for good treatment outcome. A number of variables have been proposed (e.g.: pre-treatment weight, self esteem, personality) however, to date studies have produced inconsistent results.

Wilson (1996) suggests that clinicians and researchers should expand the scope of current CBT procedures to increase its treatment efficacy. This could be done by adding an interpersonal focus, as used in Fairburn’s IPT, intensifying cognitive restructuring and ERP procedures, treating co-morbid personality disorders and individualising treatment approaches.
From a clinical viewpoint, expanding CBT would probably result in an increase in the cost of treatment per patient, especially if that treatment was carried out on an individual basis. As a result, the value of adopting a stepwise approach to treatment has been discussed. Guided self help (Cooper et al, 1994) brief psychoeducational groups (Olmstead et al, 1991) and short form CBT programs (Waller et al, 1996) have all been shown to be effective with a sub-set of patients and could be offered as a first line of treatment to the less disturbed bulimic clients. More intensive long term individual interventions could then be utilised for those who are resistant to change. Research is therefore needed to investigate matching clients to the most appropriate treatment approach.
References


Concern has been raised regarding a relationship between two clients of the same sex but of differing levels of ability living in a staffed home.

What are the areas that need to be considered when reflecting on this relationship, with specific reference to consent and policy issues?

September 1997

Year 1
Introduction

Historically, the expression of sexuality in people with learning disabilities (LD) has been feared and consequently suppressed. These fears were fuelled by myths and misconceptions, that people with LD were dangerously oversexed and detrimental to the populations gene pool, if allowed to have children. Alternatively, they were seen to be like innocent children, who should therefore be forbidden to have sex. Since the civil rights movements and sexual revolution of the sixties, and the introduction of the principle of normalisation, service providers have been forced to address issues of sexual activity among people with a learning disability. The issues that need considering are complex and many, stemming from the fact that service providers have a difficult dual obligation to help people with learning disabilities express their sexuality appropriately whilst also protecting them from harm.

It is not an uncommon scenario for service providers to be faced with issues regarding a relationship between two clients living together in the same residential home. It is also not uncommon for the clients to be the same sex and functioning at different levels of ability. In these circumstances, a number of important issues need addressing to help users exercise their right to have relationships whilst preventing exploitation, abuse or impingement of any other persons rights. This essay will discuss these issues with the assumption that the nature of the clients relationship is sexual. However, it is important to note that physical or emotional abuse or exploitation can also occur in non-sexual relationships.

The Need For Policies

Service providers for people with LD often find issues of sexuality complex and difficult to address without the help of formalised policies. Without standard procedures to follow, there is a danger that sexual behaviour of service users will be addressed, based purely on individual staff attitudes towards sexuality (Striar and Ensor, 1986). Brantlinger(1983), Johnson and Davis (1989) and Murray and Minnes (1994) assessed staff attitudes towards the sexuality of persons with intellectual disabilities and found considerable variation of attitudes based upon characteristics of
the staff surveyed. Younger, and better educated staff were found to have more liberal attitudes. Professional staff were found to have significantly more liberal attitudes than direct care staff (Murray and Minnes, 1994). Johnson and Davis reported higher levels of disagreement on issues of abortion, sterilisation and homosexuality.

Clearly, without guidelines, varying staff attitudes will differentially affect the way sexuality in persons with LD is “managed”. Overly conservative or anxious staff may repress sexual behaviour for fear of scandal, exploitation and abuse and therefore impinge on the rights of people with LD to express their sexuality. On the other hand, situations involving abuse or potential harm to service users might be unintentionally missed by overly liberal staff.

The implementation of sexuality policies helps to strike a balance between protecting the residents needs and rights and providing a consensus for staff behaviour towards residents’ sexual activities.

Cambridge and McCarthy (1997) discusses a case study of the development and implementation of a sexuality policy for a learning disability service. The policy was developed based on the needs and rights of service users and consideration of staff responsibility to protect service users from physical and psychological harm. Derived from a consultancy process, a policy was designed which incorporated salient issues that most services should consider in addressing sexuality in this population. These included;

- Sexual abuse and exploitation, with clear definitions of consent and abuse, reporting procedures and protection of victims.
- Users rights to sex education and training for staff.
- Encouragement of independence and privacy and discouragement of inappropriate sexual behaviour (e.g.: public masturbation or nudity, exploitation)
- Guidelines for determining consent, staff actions, the law on sexuality and responsibilities of the service.
• Acceptance and appropriate facilitation of same sex relationships and responds to expression of homophobic views by other service users or staff.
• Education, choice and use of contraception
• Degrees of client confidentiality and privacy
• Education on HIV and sexual health, and encouragement of safer sex practices, including availability of condoms and safeguards for HIV testing.

Not all sexuality policies are balanced to serve the needs of users and staff alike. Sundram and Stavis (1994), state that in some American agencies all sexual behaviour is prohibited by formal policies or discouraged by providing no privacy or sex education to residents. Even with policies that appear well balanced on face value, according to Zuker-Weiss (1994), often there are still gaps between what is actually done and what is declared as correct in the areas of sex education and legitimate sexual expression.

**Issues Of Consent**

One of the first considerations made by service providers is whether each client in question is consenting or able to consent to have a sexual relationship. According to the law, consent constitutes three important elements; a) knowledge of the important aspects of a decision and its risks and benefits b) understanding of knowledge needed to make that decision c) voluntary agreement, not subject to coercion, with an understanding of choice and ability to exercise that choice (Stavis et al, 1991).

Therefore, consenting to sex requires each individual to comprehend the nature and mechanics of the act, any likely consequences and the social rules involved in sexual expression.

**Informed Consent vs. Sexual Abuse**

Due to the nature of their disability and consequent residential and social environments, many people with LD, particularly those functioning within the severe range of disability, have a diminished competency for providing informed consent for sex. Not only do many lack the cognitive ability to fully comprehend all the aspects of sexual behaviour, they also lack the opportunity to experience and learn it. In addition,
people with LD are often suggestible and many have problems with communication, making it difficult to say “no” or reject unwanted sexual advances. These difficulties make people with LD vulnerable to sexual abuse or exploitation. Mansell et al, (1992), reported that for many people with LD, sexual abuse occurs repeatedly and often over protracted periods of time in a variety of settings. The occurrence of abuse has a lifelong impact on the victim (Cole, 1991).

According to Brown and Turk (1992) sex is abusive if a) the person withholds their consent b) the person is unable to give consent or c) some other barriers to consent are present. A barrier to consent might include pressures or bribes or not appreciating the consequences of saying yes to sex (Cambridge, 1997). Not only are people with LD more vulnerable to abuse because of difficulties with consent, they also often lack the communication skills to effectively disclose details about an abusive act, or fear reprisal or rejection if they do. In addition, people with LD are more vulnerable to behave in sexually abusive ways because of difficulties with consent, history of abnormal upbringing and learning, loneliness and lack of legitimate and appropriate opportunities for sexual expression (Zuker-Weiss, 1994), possible side effects of medication and the impact of brain damage such as memory problems and disinhibition. Sexual policies should therefore aim to define sexually offending behaviour and offer staff, guidelines for appropriate assessment and action to take. In many cases, staff training will be an essential provision to increase awareness of physical and psychological signs of abuse, mandatory reporting and legal procedures.

**Protection vs. Users Rights.**

People in the general population utilise their knowledge and decision making abilities and experience to ensure that the risk of sexual abuse, assault or rape is at its lowest. As this is a difficult process for people with LD, it is the responsibility of the service providers to protect and ensure the safety of their users. However, it is also the service providers responsibility to ensure that the users rights to express their sexuality are not curtailed as a result of overprotection and negative judgmental attitudes. Service users have the right to personal choice, privacy, sex education, and legal and mutual consenting sex. Their rights also extend to feeling safe and happy about sex.
and being protected from unwanted sexual contact, abuse or exploitation. State laws regarding sexual abuse and exploitation reflect the aim of protecting the public from harm. However, these laws which are designed to protect people with LD often work to exclude them from their rights to engage in mutual sexual behaviours. Most people with LD, and particularly those with severe LD, would find it difficult to demonstrate the competency and capacity to consent to sex using the present legal criteria.

**Determining Mutual, Informed Consent and Risk of Sexual Abuse.**

Effective assessment of mutual consent and risk of abuse is an extremely important procedure, in which Clinical Psychologists are very much involved. This is not a straightforward procedure; there are a number of issues to consider.

**Indications for competency to consent**

Niederbuhl and Morris (1993) found that particular client characteristics were related to the capacity to consent to sex, including level of learning disability, level of sexual knowledge, social adaptive age and psychiatric diagnosis. They concluded that these factors should be systematically considered for a thorough assessment of competency to consent.

**Clients Wants**

Verbal assessment of a clients wants is not always easy, particularly for people with severe LD who may have communication difficulties or might be afraid of reprimand by his or her sexual partner or caretakers. However, observation of clients behaviours is a good indication of whether they want to engage in a particular activity. In particular, assessment is made of the clients mood and body language for signs of contentment or distress, or any attempts to escape the activity (Kaeser, 1992).

**Health Issues**

A lack of sexual knowledge may lead to the use of incorrect sexual techniques, that in turn could unintentionally cause considerable physical damage to one or both clients. There is a higher degree of physical disabilities in people with LD that may also impact on safety during sexual activities; for example, the dangers of a client having an epileptic fit during oral sex or sexual intercourse.
In addition, the criteria for “informed consent” includes having some knowledge of the potential consequences of having sex. This is particularly important in relation to the risk of sexually transmitted diseases, such as AIDS, and Hepatitis, and the risk of pregnancy in heterosexual relationships. An assessment would need to establish knowledge of contraceptives and safe sex practices.

**Personal Choice**

People with LD are often limited for choice of sexual partners, due to poor social skills, restricted residential accommodation and opportunities for meeting and spending private time alone with others. Lack of opportunity or residential restrictions are particularly important considerations when confronted with a same sex relationship between two clients. Kramer Monat-Haller (1992) makes the important distinction between same sex and homosexual activity. She defines same sex activity as sex with another person of the same sex for purposes of exploration and because that is who is available. A person is homosexual if, given a choice and freedom to make that choice, he or she chooses a partner of the same sex rather than the opposite sex.

Freedom of choice is an important element of informed consent. Yet, community residential facilities may restrict the opportunities of people with LD to exercise their right to choose their preferred sexual partner. Users may find themselves living in group homes with others of the same sex, with little opportunity to mix with opposite sex individuals. Same sex relationships may result from the need for sexual expression and may be wrongfully labelled as homosexual. Indeed, according to Thompson (1994) most men with LD who have sex with men do not have a gay identity. Wrong labelling of sexual identity may subsequently lead to even less chance of opposite sex relations and may expose residents to negative homophobic attitudes held by staff or other clients in the service. It is therefore important in these circumstances, for service providers to help users explore and develop their sexual identities, through counselling and sex and safer sex education (Davidson-Paine and Corbett, 1995).
**Risks of Abuse**

According to Kaeser (1992), it is not enough to “allow” a sexual relationship to continue, purely on establishing that both clients wish it. In addition to establishing personal choice and risks to health, service providers need to assess the potential risk for the occurrence of abuse or exploitation. This will involve establishing

- whether either client has a history of abusive behaviour or has been abused in the past.
- whether each client has the knowledge and ability to protect themselves.
- whether other client characteristics such as psychiatric illness increases the chance of abuse or exploitation occurring.

Specifically, service providers need to establish whether both clients have the ability to remove themselves from unwanted situations or have the capacity to communicate distress and alert care staff. If one client has an overly aggressive nature, this may indicate a high risk of harm to others during sexual activity (Kaeser, 1992).

The service provider has a particularly difficult assessment and decision to make when confronted with a relationship in which clients are functioning at different levels. One client functioning at a greater level of cognitive competency, increases the potential risk of abuse or exploitation. According to Kramer Monat-Haller (1992), individuals functioning at a higher level of ability may easily be led or coerced into behaviour that is abusive or inappropriate as a response to the pleasure of sexual activity. Persons functioning at a lower level of ability are less likely to have experienced or learnt about sex, or less able to effectively utilise communication and social skills to either consent or protect themselves from unwanted sexual advances.

**Users Needs And Rights**

To provide a balance between protection from abuse and opportunity for sexual expression is a considerable challenge to carers of people with L.D. According to Kaeser (1992), many services err too much on the side of caution. Instead of seeing
sexuality and sexual abuse as problems to be managed, people with LD should be empowered to make more informed and safe decisions regarding sexual activity and given greater opportunities to learn from experience. It is therefore not good enough just to establish competency for consent or appropriateness of a person's sexual behaviour. Service providers have an obligation to provide ways of increasing the user's opportunity for safe sexual expression. This is achieved by providing sex education, supervision and better residential environments.

**Environmental Considerations**

Residential environments should be structured to allow clients their right to privacy and opportunity to experience and learn about sex safely. Lack of privacy often leads to visible public displays of masturbation, assault or inappropriate displays of affection that are considered embarrassing, dangerous or in some cases illegal (Craft and Craft, 1981).

Environments can also increase the risk of victimisation and abuse. The physical structure of a residency may provide “out of the way” places where abuse can occur undetected.

**Role of Sex Education**

Sex education groups are a useful starting point for establishing the sexual experiences and needs of users as well as providing general information on sex (Cambridge and McCarthy, 1997). The content and organisation of the groups should reflect the different needs of the clients involved. For example, the level of disability will determine what concepts can be taught to clients and how they can be taught. Often it is best to separate men and women because content is found to be embarrassing and not always relevant to both sexes. Content may also differ for heterosexual and homosexual clients, although sexual identity will need to be carefully assessed beforehand. All clients should be given the opportunity to learn ways to express their sexuality appropriately and also ways of protecting themselves from victimisation. Often repetition and booster sessions are needed for clients to ensure that information is retain (Cambridge and McCarthy, 1997).
The degree to which concepts can be learnt will vary between each individual. If a client can not grasp the concepts to enable them to become more independent, then it is the service providers responsibility to act on their behalf, and use their the power to sanction any inappropriate behaviours.

Conclusions

There are a number of issues to consider when confronted with concerns regarding a same sex relationship between two clients of differing levels of ability.

1. First and foremost, the nature of the relationship needs to be established including the occurrence and nature of any sexual behaviours between the two clients.

2. It is essential that staff adhere to guidelines regarding sexuality. Clinical decisions should be driven by organisational policies rather than individual judgements. This way, coherent and standardised approaches can be made, avoiding staff anxieties and negative judgements which might impinge on clients' rights or overly liberal or complacent attitudes leading to possibilities of sexual abuse.

3. Properly trained professionals should be involved in establishing each client's ability to consent to sex and what education or intervention might be needed to enable any future ability to consent.

4. Inability to consent or inappropriate sexual behaviours often stem from restricted learning, experience or environmental restrictions. Service providers have an obligation to address these issues to meet the needs and rights of service users and provide opportunities for clients to have a safe and healthy sex life and intimate opposite or same sex relationships.

5. Service providers are obliged to act for the best interests of their clients in cases in which informed consent is not possible to achieve and clients are in risk of sexual abuse or exploitation. Typically, environmental modifications, behavioural interventions and extra supervision might be provided to decrease the risk of victimisation.
References


Kaeser, F. (1992). Can people with severe mental retardation consent to mutual sex?. *Sexuality and Disability, 10(1)*, 33-42.


CHILD AND ADOLESCENT ESSAY

Critically evaluate the adult models of PTSD and consider their relevance to PTSD in childhood

March 1998

Year 2
Introduction

The concept of Post Traumatic Stress Disorder (PTSD) was first developed in relation to adult responses to major stress. Through studies of the long-lasting psychological effects of the Second World War and Vietnam war, PTSD was identified as a coherent syndrome consisting of three major groups of symptoms; - a) distressing reoccurring recollections of the traumatic events b) avoidance of stimuli associated with the trauma c) a range of signs of increased physiological arousal (Horowitz, 1976; American Psychiatric Association, 1980). Since it was first operationalised in DSM III (American Psychiatric Association, 1980), PTSD in adult populations has been studied extensively and a number of theories developed to account for its etiology. More recently, PTSD has been a widely recognised syndrome in children who experience acute or chronic trauma. However, the symptoms of PTSD in children has been shown to vary considerable from the adult population, particularly in relation to influential developmental factors. At present, this is not reflected in any subcategories within the psychiatric classification systems (DSM IV or ICD 10) nor adequately accounted for by adult theories of PTSD.

This essay will critically evaluate the three most influential adult models of PTSD and will discuss their relevance in relation to manifestation of PTSD in children. It is concluded that an integrated biopsychosocial-developmental model, would provide a more relevant conceptualisation of PTSD in childhood.

Adult Models of PTSD.

A number of theories and theoretical models have been developed on the basis of studies of adult reactions to major traumas, such as the Vietnam war, traumatic accidents, incidents (e.g.: rapes, shootings) or natural disasters. Most theories have attempted to account for the etiology of the specific symptoms associated with PTSD, as classified in DSM and ICD. Theoretical perspectives have included psychophysiological models (De la Penna, 1984; van der Kolk et al, 1985; Ross et al, 1989), Behavioural models (Keane et al, 1985), Psychodynamic theories (Worthington, 1978; Horowitz and Kaltreider, 1980), Object Relations theories
(Brende, 1985), Cognitive appraisal theories (Janoff-Bulman, 1985, 1992; Epstein, 1990), Information Processing models (Foa et al, 1989; Chemtob et al, 1988; Creamer et al, 1992; Brewin et al, 1996), Psychosocial models (Wilson, 1977, 78; Green et al, 1985), Cybernetic (systemic) models (Williams, 1992) and a model based on Bowlby's theory of attachment (Sable, 1995).

The three most influential models for the etiology of PTSD have been a) behavioural theories, b) Cognitive-psychodynamic theories and c) cognitive appraisal and information processing models. It is primarily from these theories that DSM criteria and interventions for the treatment of PTSD have been developed.

**Behavioural (Learning) Theory.**

Based on Mowrer's two factor learning theory, Keane et al (1985), proposed that PTSD, like other anxiety disorders, is a result of classically conditioned physiological and behavioural fear responses. They propose that a traumatic events acts as an unconditioned aversive stimulus (UCS) which elicits extreme levels of physiological arousal and subjective distress. Neutral stimuli, present during the trauma serve as conditioned stimuli (CS's), which then come to elicit conditioned responses (CR's) of heightened arousal and psychological distress. Through the process of generalisation and higher order conditioning, other neutral stimuli acquire aversive overtones via association or similarity to the original conditioned stimuli.

The concept of instrumental (operant) conditioning is posited to explain avoidance behaviour in PTSD. Escape and avoidance of the CS is negatively reinforced by reduction of distress and arousal and is therefore likely to lead to avoidance of exposure to conditioned stimuli in the future.

Evidence for this model comes mainly from animal studies, although indirect evidence has been provided from studies of psychophysiological behaviour and cognitive responses of Vietnam veterans to combat situations (e.g.: Blanchard et al, 1982; Malloy et al, 1983).
Treatments of PTSD within a behavioural framework has fallen into two approaches; exposure-based therapies to reduce arousal to conditioned stimuli and stress management techniques, which focus on the acquisition of skills to cope with the symptoms of PTSD.

Critique

This theory gives us an uncomplicated account for the acquisition of fear to trauma related cues which were previously void of aversive associations. Through the process of generalisation and higher order conditioning, it can explain why victims of PTSD develop fear reactions to a multitude of seemingly unrelated stimuli. It is also helpful in explaining avoidance behaviour of PTSD sufferers, to non-dangerous situations. However, it fails to adequately account for other important symptoms found in PTSD, such as flashbacks, intrusive thoughts, nightmares or startle responses. Not enough attention is paid to higher order constructs (cognition’s) such as expectations, attributions motivations etc., that may explain individual differences in the development of PTSD. Higher order processing may also play an important role in avoidance behaviour, as opposed to negative reinforcement schedules. For example, two factor theory claims that avoidance is reinforced by reduction of fear or anxiety. However, direct evidence for the presence of fear has not always been observed (Rescorla and Solomon, 1967). Expectancy may play an important role in that a person expects that avoidance will result in the omission of fear rather than a direct reduction of fear (e.g.: Seligman and Johnson, 1973).

Two factor theory would posit that exposure to feared stimuli would reduce anxiety through a process of extinction. However, this is not found in cases of exposure with PTSD sufferers. Keane puts this down to incomplete exposure to all traumatic stimuli and to the sufferers avoidance of thoughts and memories, plus a failure to elicit emotions associated with salient trauma memories. Although his hypotheses appear feasible, his explanations inadvertently step outside of the behavioural model, by acknowledging salient cognitive and emotional structures, which would appear to be important determinants for who develops PTSD.
Psychodynamic Models

Early psychodynamic models of PTSD placed a great emphasis on individual characteristics and pre-trauma psychic conflicts as major etiological factors (Worthington, 1978). A later and more influential reformulation, combined psychodynamic principles with information processing theory (Horowitz and Kaltreider, 1980). Horowitz conceptualised that traumatic events contain a massive amount of internal and external information which does not fit into the victims existing cognitive schemata. Intense emotional distress results from the discrepancy between external and internal information, and therefore, the victim shunts this new information out of awareness through the ego defence mechanism of denial, manifested in emotional numbing, psychic amnesia and dissociation. Intrusion of the information in the form of flashbacks, nightmares and intrusive thoughts occurs due to the tendency for humans to process information until assimilated or accommodated into existing cognitive structures. Oscillations between intrusion and denial-numbing continues until the new information becomes part of long term models and inner schemata.

Based on the above theory, Horowitz (1973, 74) classified treatment procedures according to the individuals presenting symptomatology. Intrusive thoughts and flashbacks were dealt with supportive techniques to relieve distress and aid repression. Extreme denial would be addressed using “uncovering” techniques, to reduce control and encourage catharsis.

Critique

This theory appears to account for most of the symptoms manifested in adult PTSD, such as flashbacks, intrusive thoughts and emotional numbing. Horowitz also has a limited explanation of the individualistic presentations of PTSD, which she associates with character traits, cognitive styles, pre-morbid patterns of conflict and coping mechanisms, including the availability of social support.

Horowitz’s theory of PTSD is an interpersonal explanation of symptom formation and therefore fails to account for intrapersonal factors in the development of PTSD, such as the qualitative nature of the traumatic event or environmental factors such as family
dynamics. She does mention the role of social support, but does not explain how this might interact with information processing and ego defence mechanisms. She also places little emphasis on the power of individual cognitive processes such as attributions or expectations in interpreting the meaning of the event. She details the existence of existing schemata but provides little information on the way in which cognitive structures fail to accommodate new information from a traumatic experience. In addition, the efficacy of psychodynamic psychotherapy of PTSD based on this model has not be unequivocally established, mainly due to mixed research findings and a lack of properly controlled studies within this area.

*Cognitive Models*

There are a core number of assumptions of cognitive theories of PTSD. Individuals are believed to bring to the traumatic experience, a set of pre-existing beliefs and models of their own self and the world. Traumatic experience provides information which is highly salient and incompatible with existing cognitive structures. Attempts to assimilate and accommodate the new information with existing structures leads to the various symptoms of PTSD. Resolution of symptoms occurs when the information has been integrated into existing or modified schemata.

There are two main types of cognitive theories for PTSD; cognitive-appraisal theories and information processing theories.

Cognitive appraisal theories such as Janoff-Bulman (1985) and Epstein (1990) emphasise the impact of the trauma on an individuals life and highlights the massive readjustment often needed to integrate the experience into individual pre-existing views of the world. Symptoms of PTSD are produced by a threatening event which invalidates an individuals personal theory of self and the world (e.g.: assumptions regarding personal invulnerability, perception of the world as meaningful or comprehensible and the view of self in a positive light).
Information processing models of PTSD focus primarily on how trauma related information is represented in an individual's cognitive structures and how it is subsequently processed.

Foa ad Kozak (1986) applied Lang's concept of fear structures in an information processing model of PTSD that centres around the formation of fear networks in memory. Fear networks are cognitive structures that are developed as a result of a traumatic event. These structures encompass information about the traumatic event, cognitive, behavioural and physiological reactions to the trauma and interoceptive information that links these stimulus and response elements together. Fear networks are activated by triggering stimuli (reminders of the trauma), causing information to enter consciousness (intrusions, flashbacks). Attempts by the individual to suppress activation leads to clusters of avoidance symptoms. In addition, a positive feedback loop due to the uncontrollable and unpredictable nature of the traumatic event, and subsequent disruptions to attention and memory processes during trauma, fear networks are difficult to assimilate into existing networks of schemata which posit that the world is controllable and predictable. Extinction of fear symptoms involves assimilation and accommodation via activation of fear networks or the provision of incompatible information.

Critique

These theories provide a greater understanding of the cognitive processes underlying PTSD and accounts for individual attributions and interpretations of events which may effect individual presentations of PTSD symptomatology. The therapeutic role of providing incompatible information to assimilate fear networks, highlights the role of social support in providing that information and also highlights the processes underlying the success of exposure based treatments.

Specifically, these theories allow for a continuum of normal to pathological responses to trauma, determined by each individual's own belief systems (i.e.: individuals pre-morbid cognition's are acting as the main predictor variable for developing PTSD). However, these theories struggle to explain the generalisation of fear to stimuli outside the realm of the traumatic experience, which would not be encapsulated within a fear network or considered a threat to the individual through processes of cognitive
appraisal. It would seem that behavioural principles may be a more relevant explanation for this. Unlike the Horowitz model, these theories do not adequately consider mechanisms involved in denial and numbing processes and psychogenic amnesia. That is, they do not consider the role of unconscious defence mechanisms within the sufferers avoidance strategies. Similar to Horowitz, these theories do not account for factors external to the individual in the development of PTSD, such as family environments, developmental stages, cultural attitudes and attachment relationships.

In short, all these theories lack a contextual and developmental outlook, which would certainly seem even more important when considering PTSD in children.

**Adult vs Childhood PTSD: The Issues**

Children manifest many of the same reactions to trauma as adults, and PTSD has become a more widely accepted syndrome occurring in children. However, there are a number of salient differences between PTSD as it presents in adults and children, which question the validity of general theoretical models in accounting for both.

**Presenting Symptoms and DSM Criteria.**

The classification of PTSD in psychiatric diagnostic tools such as DSM and ICD, was originally validated, based on studies of adult populations and not children. Although the validity of PTSD in children has been recognised in DSM-IV and empirically tested (Saigh, 1989), research and clinical observations have noted a vast difference in the symptomatology of PTSD between children and adults. These differences are not acknowledged or classified in DSM criteria for PTSD nor are they accounted for by theories developed from adult studies of PTSD.

As well as the tripartite grouping of symptoms - re-experiencing, avoidance reactions and increased arousal, children and adolescents commonly describe or present with a range of other reactions (Yule, 1991; Pynoos and Nader, 1993). These include separation and attachment difficulties, lower IQ and learning disabilities,
developmental delays manifested in poor language and communication, impaired self concept, failure to thrive, posttraumatic play and somatic problems.

Like adults, children do exhibit fear and avoidance behaviours. However, flashbacks are not common in children. Children tend to relive trauma through play, dreams and waking intrusive recall. Children also do not show evidence of psychogenic amnesia or the same degree of emotional numbing as adults. (Terr, 1983). This would suggest that there are other processes occurring within children suffering from trauma, which is not accounted for by either the psychodynamic or cognitive theories reviewed above.

*Developmental Influences on Childhood PTSD.*

What all the adult models of PTSD fail to do, is account for the influence of developmental factors in the presentation of PTSD in childhood. Symptomatology has been linked to the individuals level of cognitive, ego and psychosocial development at the time of the trauma (Schwartz et al, 1994).

Terr (1985), used Erikson's model of psychosocial development to explain PTSD symptomatology in children and adolescents. He concluded that children appear to be especially vulnerable to a collapse of basic trust and autonomy after trauma because of being at a developmental stage in which trust and autonomy is less consolidated compared to adults and adolescents. Traumatised adolescents have been described as having impaired identity formation as a result of disruptions in their psychosocial development (Wilson, 1980).

It has be noted that children do not typically manifest symptoms of psychogenic amnesia and flashbacks to shut out intrusive and distressing images(Lyons, 1987), perhaps due to underdeveloped ego defence mechanisms, such as denial. Instead, children have been observed to use fantasy or imagined action to mitigate traumatic distress.

A child’s cognitive capacity will also govern the complexity of understanding of the trauma, the meaning of the trauma in the child’s life (Pynoos, 1989) and ways in which it is processed (Mowbray, 1988). Dollinger (1986) found that children, like adults,
attempt to integrate and master their experience of trauma, to ask questions and determine the meaning of the event. This would seem to mirror information processing as seen in adult sufferers. However, cognitive development is very likely to have an effect on this process in children. Indeed, children’s notions of causality of events have been noted to reflect Piaget’s stages of cognitive development. Younger children use magical, fantasy explanations. From this, evolves egocentric and concrete concepts and finally abstract explanations incorporating multiple causal factors and moral reasoning (Schwartz et al, 1994).

Appraisal of a traumatic event as a stressor has also been linked to development. Thus, what would be experienced as a stressor for an adolescent might not be so traumatic for a younger child and visa versa (Schwartz et al, 1994). In addition, children, particularly younger ones, are less likely to have consolidated cognitive schemata about their own self and the world in which to assimilate and accommodate trauma information. From the theoretical perspective of the cognitive appraisal model, one could hypothesise that individuals who lack coherent cognitive schemata, would find it easier to assimilate new information and therefore present with few symptoms of PTSD. Indeed, Green et al (1991) found that younger children showed less symptoms. However, this has not always the case. Lonigan et al (1991) found the opposite to Green and Misch et al (1993) found that children as young as two exhibited distress and could communicate their experiences through age appropriate means. It would therefore appear that other factors, apart from internal cognitive processes are playing important roles. These could be other developmental factors such as physiological development, intellectual development, temperament and contextual factors.

*Pre-morbid and Contextual Influences on Childhood PTSD.*

Some adult models of PTSD take into account the nature of the traumatic event in terms of severity and duration, as influential in the etiology of PTSD. Cybernetic models account for the influences of pre-morbid family environments and other contextual factors in the development and resolution of PTSD symptomatology (e.g.: Williams, 1992). Contextual factors have been found to be particularly important in the etiology of childhood PTSD, especially in younger children. Pynoos et al, (1987).
and others (e.g.: Bradburn, 1991), have found that a child’s degree of exposure to a traumatic event is a critical variable in the development of symptoms. For children, pre-morbid family functioning and post trauma parental reactions have been found to have a significant effect on symptom development and outcome (McFarlane (1987; Newman, 1976; Green et al, 1991). Family factors could be conceptualised as influential through processes of observational learning (modelling) of traumatic reactions (Rachman, 1977), effects of early attachment relationships and subsequent separation anxiety (Sable, 1995), behaviourally conditioned symptoms of PTSD (Dollinger et al 1984) within the family environment or differing levels of support given to the traumatised individual.

Conclusions

There are a number of theoretical models of PTSD based on empirical studies on adult populations. None are above critical comment, and it would seem that an integration of models would increase our understanding of the etiology of PTSD and the processes maintaining PTSD symptomatology.

Individually, adult models of PTSD also seem inadequate in their explanation of PTSD in children because, for the following main reasons;

a) they are unable to account for the vast range of symptoms that children exhibit as a result of trauma, which adults do not.

b) equally important, adult models do not explain the absence of symptoms in children suffering from PTSD such as flashbacks and psychogenic amnesia.

c) they do not account for developmental factors, such as psychosocial and cognitive development in the etiology of symptoms.

d) They fail to adequately account for the full impact of disruptions of attachment in childhood, childhood reactions to bereavement and loss, pre-morbid family functioning and the role of observational learning from parents, siblings and peers.

In conclusion, new theories and conceptualisations need to be developed, based on studies of children, to integrate all the salient etiological factors within a developmental framework. This would help researchers and particularly clinicians in understanding
the processes and likely reactions to trauma within individuals at different ages. Intervention strategies based within a more relevant theoretical and empirical background may then be developed.
References


NEUROPSYCHOLOGY ESSAY

Discuss the methodological considerations when assessing for dementia and when attempting to distinguish between different possible diagnoses

December 1998

Year 2
**Introduction**

Neuropsychological assessment aims to assist in the differential diagnosis of dementia and/or to provide information on a person’s level of functioning from which treatment or management plans can be developed and evaluated. Accurate diagnosis of dementia is vital, as misdiagnosis may cause a patient’s family the unwarranted burden of anticipating a progressive deterioration in their loved one, or may prevent the application of appropriate effective treatment regimes which may vastly improve the patient's condition. Misdiagnosis can often occur because of the existence of conditions like depression which can mimic dementia, or because of invalid test scores as a result of methodological problems in neuropsychological assessment.

**Methodological Issues In the Neuropsychological Assessment Of Dementia**

**Diagnostic Criteria**

It is essential that neurologists and neuropsychologist have clear and precise diagnostic criteria in order to diagnosis dementia accurately. Numerous definitions have been proposed over recent years, not without some controversy. Four diagnostic criteria are currently available. DSM-IV (APA, 1994) and ICD-10 (WHO, 1993) both provide general outlines for the diagnosis of dementia but do not provide means of operationalizing their criteria. The State of California Alzheimer’s Disease Diagnostic and Treatment Centers (Chui et al, 1992) and the National Institute of Neurological Disorders and Stroke and the Association Internationale pour la Recherche et L’Enseignement en Neurosciences (NINDS-AIREN: Roman et al, 1993) are developments of the first two and provide operational definitions.

Essentially, the above four sets of criteria are the same; they only differ in detail. There is an emphasis on the development and progression of multiple cognitive deficits, which represents a decline from previous levels of ability and causes impairment in social and occupational functioning. All the above criteria have limitations, the main one being that dementia is based on the clinical description of
Alzheimer’s Disease (AD) and provide less specific criteria for vascular dementia, sub-cortical dementia’s and reversible dementia’s. The effects of variable aetiologies of dementia are not specified, and the need for a clear loss of cognitive functioning makes early stage dementia difficult to detect (Bowler and Hachinski, 1996).

**Using a Comprehensive Battery of Tests**

In relation to current diagnostic criteria for dementia, it is important for the neuropsychologist to assess multiple areas of cognitive functioning, including pre-morbid ability. These areas usually include attention, visual, verbal and recognition memory, language skills, general intellectual functioning, visual-spatial skills, motor and sensory-perceptual functions (Filskov, 1983).

An objective evaluation of emotional functioning is also useful to differentiate an organic dementia from cognitive deficits associated with psychological factors such as depression or anxiety (Kurlychek and Hazlewood, 1984).

**Gathering Supplemental Data**

Obtaining background information and referral information is as important in the assessment of dementia as the administration of the psychometric tests. Of particular importance is the establishment of pre-morbid status, the onset and current severity of perceived cognitive, behavioural or emotional changes and any significant life events that might have paralleled those changes (Kurlychek and Hazlewood, 1984). This information can assist in establishing the possible existence of pseudodementia (such as depression) or the possible cause for organic dementia. For more severely impaired patients, information may need to be verified and/or expanded via family members or carers.

**Individual Influences on Cognitive Functioning**

It is essential that clinicians are aware of the degree to which cognitive functioning can be influenced by individual traits such as age, education, occupation, culture and life experiences. All these factors can effect test performance in a number of ways and
therefore must be considered when interpreting the results of any neuropsychological investigation.

**Normal vs. abnormal age related changes.**

One of the first questions to be answered from a neuropsychological assessment of dementia is whether an individual's level of cognitive function is abnormally low and if so, whether there has been a significant degree of change from a pre-morbid level of functioning. In order to answer these questions, the clinician must have a good knowledge of the cognitive changes which occur as the result of the normal ageing process. The relationship between age and performance on neuropsychological tests is somewhat variable (Albert and Moss, 1988). Research on memory loss associated with ageing, points to minimal deterioration in short term and remote memory with more marked deficits in long term memory (Poon, 1985). These expected changes in memory with ageing have been classified in DSM-IV as "mild neurocognitive deficits" (APA, 1994). For other areas of cognitive functioning, Van Gorp et al (1990) found that speed of information processing declined significantly with age while verbal and non verbal cognitive factors did not differ significantly in patients between the ages of 57 and 85.

**Pre-Morbid Level Of Education or Intellectual Functioning.**

A patient's pre-morbid level of intellectual ability can bring its own challenges for the neuropsychologist. Patients with a low level of intelligence or education may produce flooring effects on most standard neuropsychological tests such as the WAIS. Tests that have been used for these individuals such as the Peabody Picture Vocabulary Test, may not be suitable for the assessment of dementia. Clinicians assessing for dementia in learning disabled populations have used functional assessments to help determine if current levels of functioning represent a decline from previous levels.

Patients with superior intelligence also pose problems as they may produce ceiling effects on standard tests (Weintraub and Mesulam, 1985). Interpretation of test performance with these individuals requires a thorough understanding of the expected decline as the result of normal ageing vs. a dementing disease (Naugle et al, 1990).
Methodological Problems In Neuropsychological Tests

Norm Reference Testing

Due to age related changes and cultural differences in certain areas of cognitive functioning, interpretation of performance on any test requires data which are normed on people from a variety of different ages groups, ethnic groups, and educational backgrounds, as well as on patients with various neurological, psychological and physical diagnoses. Unfortunately, many tests used in neuropsychology are lacking in this respect, and much criticism has been levelled against psychometric and neuropsychological tests because of their educational, occupational and sociocultural bias. In particular many tests do not provide normed data for the older population in which dementia is of higher prevalence. For example, the revised version of the WAIS includes normative data from American and British populations, only up to the age of 74 years, which is wholly inadequate, particularly in view of the rapidly increasing population over the age of 80 (Hart and Semple, 1990).

When tests do provide norms, these have often been acquired using university populations of above normal intelligence who are usually Caucasian and English speaking. In contrast, patients tend to be less well educated, less affluent, with lower level of health (Pachana et al 1996). Consequently, individuals from deprived backgrounds, those with limited education or from different cultures tend to underperform on these tests and may therefore be falsely considered cases of dementia. This re-emphasises the importance of establishing cognitive deterioration from a higher level of ability in order to diagnose an acquired impairment (Hart and Semple, 1990).

Normative data can also become invalid over time, due to generational differences (cohort effects) in knowledge, education, performance, lifestyles etc (Hart and Semple, 1990). In relation to this, test materials can quickly become old and outdated. The use of revised tests and new test norms is therefore essential for accurate assessment of cognitive functioning.
Assessment Of Cognitive Decline

The measurement of pre-morbid intelligence has been a main assessment for diagnosis of dementia due to the importance of establishing significant cognitive deterioration. This has been achieved by using tests of functioning known to be resistant to organic brain disease (e.g.: Vocabulary and Information on the WAIS; National Adult Reading Test-Revised: NART-R), or by estimation using patient's educational and occupational histories (Barona formula; Barona et al, 1984) or a combination of both methods. However, research has shown that WAIS subtests such as Vocabulary can be sensitive to change in dementia patients (Larrabee et al, 1985) and high standard errors of estimation have also been found when using the Barona formula. The NART is still used as the most accurate measure of pre-morbid intelligence, but this test also has limitations which must be observed. For example, it is unsuitable for patients who are blind or have speech production problems and it is also poor at making discriminations in very high or very low bands of intelligence (Morris and Kopelman, 1994).

Assessment In Different Stages Of Dementia

Diagnosing dementia in the early stage of the disease demands the ability to differentiate subtle abnormal decline from normal age related changes (Pachana et al, 1996). Tests which are most sensitive to dementia at the earlier stages of the disease are not necessarily the same as those giving the better discrimination later on in the course of the disease. Most tests used in neuropsychology have established diagnostic validity using samples of subjects for which a diagnosis of dementia is clear (often the later stage of the illness). This is likely to overestimate a test's discriminative power for patients with dementia in early stages of development (the stage when they usually get referred for neuropsychological assessment). There are few tests which are highly sensitive to cognitive changes in early stage dementia and research needs to validate further tests for diagnosis in this disease stage (Miller and Morris, 1994).

The assessment of severe or advanced dementia, normally performed for reasons other than for diagnosis, can also be a difficult procedure. Many tests used for early stage dementia will produce flooring effects later on in the disease process and therefore the
assessment is likely to be inaccurate. Two instruments to date have been designed and validated for the assessment of patients with advanced dementia, who are likely to have limited communication skills and understanding: the Test for Severe Impairment (TSI: Albert and Cohen, 1992) and the Severe Impairment Battery (SIB: Saxon et al, 1990). Neuropsychologists may also need to use third party reports of decline and current behavioural and social functioning, to assist in a more accurate assessment.

*Base Rates*

Another issues raised in the literature is that of base rates (Meehl and Rosen, 1955). The base rate is the frequency with which a certain diagnosis of concern arises in the sample in which the test is being used (Miller and Morris, 1994). A test may be able to discriminate well (90% accuracy) in a sample where 50% of subjects have depression and 50% have dementia. If however, in the sample, 90% of patients turn out to be dementing, then 90% diagnostic accuracy can be achieved by guessing that each individual has dementia. In practice therefore, the diagnostic accuracy of a test will depend on the proportion of subjects tested who are likely to have dementia (Crawford et al, 1994). Base rates therefore need to be taken into consideration when making diagnostic decisions. The Kendrick Battery (Kendrick, 1985) for the detection of dementia is one of the few tests to take base rates into consideration.

*Group vs. Individual Diagnosis*

Most diagnostic tests of dementia, used by neuropsychologists have been validated based on comparisons of group means, whereas in clinical practice, these tests are used to make decisions about individual patients (Mitrushina and Fuld, 1990). There is therefore an appreciable chance that a diagnostic decision based on these tests could be wrong, and clinicians need to be aware of this.

*Test-retest Reliability*

Once initial assessment has occurred, further decline becomes measurable by direct means, involving the comparison of data from two occasions. In order to make this process valid, the tests used in the assessments must have high test-retest reliability or exist in alternate forms (e.g.: Adult Memory and Information Processing Battery).
Test-retest reliability data are lacking for many psychometric tests which have a long history of use in the diagnosis of dementia (Hart and Semple, 1990).

**Population characteristics; assessing the elderly**

Special considerations are needed when assessing older adults for possible dementia. Ageing is associated with an increase in the prevalence of systemic disease processes (e.g.: cardio-vascular disease) which can often have direct or indirect effects (via medication) on cognitive functioning (e.g. Hale et al, 1992). As mentioned early, psychiatric disturbance such as depression is also high in prevalence in this population and can also produce cognitive impairments (Caine, 1981), which can confuse diagnosis.

The elderly population are more likely to have sensory or physical handicaps (e.g.: arthritis) which can affect performance (O'Neill and Calhoun, 1975). It is therefore important for the clinician to establish that sensory functioning is adequate enough for an assessment to be carried out reliably. Elderly people should be wearing glasses or hearing aids if needed. The environment in which testing is carried out should be quiet, well lit and accessible by wheelchair.

**Older patients may find neuropsychological testing somewhat threatening and additionally, dementing patients may be confused as to the nature of the tests and may lack insight into their disability (Morris and Kopelman, 1994). The neuropsychologist will need to take some time building rapport with these patients, in order to reduce any anxiety and maximise motivation.**

Finally, older people may tire easily and may be upset or unwilling to continue with a long assessment procedure, particularly if they find the tasks too complex and begin to fail. Assessment sessions may need to be slower in pace, with frequent breaks. Tests should be carefully selected, bearing in mind their level of complexity and the length of time needed for administration. Often shortened versions of tests such as the WAIS are used or specially constructed brief tests such as the Kendrick Cognitive Tests for the Elderly (Kendrick, 1985) or the Clifton Assessment Procedures for the Elderly (CAPE) (Pattie and Gilleard, 1979).
Differential Diagnosis of Dementia

The large array of disorders that may mimic dementia, as well as the numerous causes of dementia, makes diagnosis a difficult task. Usually, transitory causes of cognitive impairment such as delirium and acute toxic substances or diseases have been established or ruled out by medical examinations (blood tests, etc), prior to referral for neuropsychological assessment. Many diagnostic referral requests centre around the question of whether a patient has a functional or early organic dementia. If an organic aetiology is established, assessment may then attempt to indicate its likely cause. This has important implications for the possible application of treatment regimes or management plans.

Organic vs. Functional Dementia

There are a number of psychiatric conditions which can give rise to clinical symptoms of dementia. These include schizophrenia, hysteria, mania and paranoia. However, depression is the most common cause of a so called pseudodementia (Lishman, 1987). Patients with functional dementia may present with impairments in memory and concentration, orientation and defective knowledge of current events, while emotional disturbance seems less apparent. These functional symptoms can result in frequent diagnostic error in the neuropsychological assessment of dementia, particularly in the elderly population where between 4-10% suffer from moderate to severe depression (e.g.: Blazer and Williams, 1980). The reported failure to recognise depression as the cause of dementia ranges from 2-15% (Hart and Semple, 1990).

Diagnostic assessment becomes even more problematic when dementia and depression co-exist. In these circumstances, neuropsychological test results will often be consistent with an organic diagnosis while detection and possible treatment of secondary depression is missed (Hart and Semple, 1990).

Much research has attempted to profile the cognitive performance of depressed patients, in order to help differentiate them from those with dementia. There is evidence to indicate impairment of new verbal learning (Weingartner et al, 1982), concentration and attention in depression, but with less impairment in language skills,
arithmetic, motor praxis (e.g.: Caine, 1981) and cued verbal and visual recall (Coughlan and Hollows, 1984) compared to dementing patients. However, diagnostic errors still occur when too much weight is attached to changes in cognition alone (e.g.: Lishman, 1987). The importance of obtaining historical data, such as past and current psychiatric illness, sudden or gradual onset of dementia and associated life events, is now recognised as a standard procedure in helping to differentiate between organic and functional aetiology (e.g.: Wells, 1979).

**Generalised Vs Focal Organic Impairment**

A diagnosis of dementia requires that cognitive impairment is multiple and general as opposed to focal. Some focal syndromes that may be mistaken for dementia include amnesiac disorders, dysphasia, parietal lobe lesions and frontal lobe lesions. These syndromes often involve impairments in a number of cognitive functions (e.g.: language memory, personality changes), indicating a deterioration from a previous level of intellectual ability. Differentiation from dementia in these patients may be difficult for the neuropsychologist. However, distinctive features of focal damage for clinicians to watch out for include the circumscribed nature of the deficits, associated focal neurological signs, sudden onset, and improvement over time (McLean, 1987).

**Aetiological Diagnosis Of Dementia**

Once the presence of an organic dementia is established, the neuropsychologist might be asked to indicate its underlying aetiology. Differentiation between the different aetiologies is important because the course, treatment, genetic risk and prognosis differ in each case.

For the neuropsychologist, one of the main clinical tasks is the differentiation between a primary degenerative disorder such as Alzheimer’s Disease (AD) and vascular dementia (VaD) (Hart and Semple, 1990); a dementia resulting from cardiovascular disease. This area has received much attention. Current criteria for multi-infarct dementia is still heavily based on the development of an Ischaemic Rating Scale by Hachinski et al (1975), which has been criticised for producing an unacceptably high number of diagnostic errors (Liston and La Rue, 1983). However, it is generally
recognised that AD is a slowly progressive dementia whereas VaD is associated with a step-wise progression, due to the occurrence of small but multiple infarcts in the brain. In VaD, focal features might be more prominent, whereas in AD the pattern of cognitive impairment may be expected to be more even. However, in practice, AD may affect certain parts of the brain first thus complicating diagnosis early on in the course of the disease (e.g.: Neary et al, 1986, 1988).

Clinician’s attempting to distinguish forms of sub-cortical dementia such as Parkinson’s and Huntington’s, from AD encounter the same problems as those in differentiating AD from VaD, particularly in the early stages of the disease, when cognitive manifestations can be fairly mild (Salmon et al, 1989). However, these dementia’s are much rarer than AD and produce other symptoms which can give good clues to differential diagnosis, such as extrapyramidal motor disorders.

**Summary**

- Clear and specific criteria is essential in guiding diagnosis of dementia. Testing multiple areas of cognitive functioning and gathering supplemental background data is vital for developing a comprehensive neuropsychology assessment.
- The effects of individual differences such as education, culture, age and concurrent psychiatric pathology must be taken into consideration when interpreting test data.
- It is critical for accurate diagnosis of dementia, to have knowledge of cognitive and functional changes which occur as a result of normal ageing.
- When assessing for dementia in older populations, sensitivity to the medical, physical and psychological problems encountered by older patients is needed.
- Understanding methodological limitations of neuropsychological test can aid appropriate test selection and interpretation.
- Having knowledge of the various causes of dementia and their associated cognitive, behavioural and psychological manifestations is critical for the diagnosis of underlying aetiology.
References


SECTION TWO

CLINICAL DOSSIER
CLINICAL PLACEMENT SUMMARIES
ADULT MENTAL HEALTH CORE PLACEMENT

Location: East Surrey NHS Trust, Horley
Supervisor: Dr David Brock

CLINICAL EXPERIENCE

Client Demographics
- 12 clients (9 female, 3 male) between the ages of 23 and 71.

Presenting Problems
- Depression and low self esteem
- Social Anxiety
- Panic Disorder
- Agoraphobia
- Adjustment difficulties following body altering surgery
- Chronic Fatigue Syndrome
- Sexual problems
- Psychosis with cognitive deficiencies
- Difficulties with anger
- Bereavement
- Obsessive Compulsive Disorder

Assessment Procedures
- Assessment interviews within a Cognitive Behavioural Therapy framework.
- Questionnaire assessments: Beck Depression and Anxiety Inventories, Padua Inventory, Personal Adjustment Questionnaire.

Interventions
- Cognitive Behavioural Therapy
- Sensate Focus Therapy for sexual problems
- Stress/Anxiety Management incorporating progressive relaxation, CBT

Other Work/Experience
- Half day teaching: Anger Management Workshop (part of CBT diploma course)
- Case presentation to CBT peer supervision group
- Presentation: CBT for Psychosomatic Disorders (45 min).
- Attendance at Departmental meetings.
- Meetings with and/or observations of other professionals (CPN, Psychiatrist, psychologists, eating disorders counsellors).
PEOPLE WITH LEARNING DISABILITIES CORE PLACEMENT

Location: Surrey Heartlands NHS Trust, Epsom
Supervisor: Liz Marlow & Zillah Webb

CLINICAL EXPERIENCE

Client Demographics
- 12 clients (9 female, 3 male) between the ages of 23 and 71 years.

Presenting Problems
- Inappropriate sexual behaviour
- Resettlement issues
- Challenging behaviour
- Psychosis and challenging behaviour
- Relationship difficulties
- Anxiety
- Needle phobia
- Sexual vulnerability

Assessment Procedures
- Brook’s “Not a child anymore” sex assessment
- HALO
- British Picture Vocabulary Scale
- Leiter International Performance Scale
- WAIS-R
- Behaviour Assessment Battery
- Staff Support Levels Assessment
- Disability Assessment Schedule
- Adaptive Behavioural Scale
- Structured Observation

Interventions
- Sex Education
- Behavioural Therapy
- Basic Cognitive Therapy

Other Work/Experience
- 1 hr Presentation to Psychology Department
- Service related research (Small scale research project)
- Participant in Community Team meetings
- Attendance at PLD SIG.
CHILD AND ADOLESCENT CORE PLACEMENT

Location: Worthing Priority Care NHS Trust
Supervisor: Jane Beal

CLINICAL EXPERIENCE

Client Demographics
- 13 clients (5 females, 8 males), between the ages of 3 and 18 years.

Presenting Problems
- Depression and anger
- Autism
- Behavioural problems – temper outbursts
- Post Traumatic Stress Disorder
- Sleeping problems
- Attachment Issues
- Attention Deficit and Hyperactivity Disorder
- Sexual Abuse
- Tourettes Syndrome
- Phobia
- Family relationship difficulties
- Bullying

Assessment Procedures
- Assessment interviews within a Cognitive Behavioural and Cognitive-Developmental framework.
- Assessment interview within a Post Milan Family Therapy framework.
- Questionnaire/Diary assessments: Beck Depression Inventory, Sleep Diaries, Behavioural Records.
- Neuropsychological Assessments: WISC-III, WPPSI-R.

Interventions
- Cognitive Behavioural Therapy.
- Parenting Skills.
- Behavioural Therapy.
- Post Milan Family Therapy.
- Therapy within systemic framework (individual clients)

Other Work/Experience
- Case presentation to specialty meeting.
- Attendance at departmental and specialty meetings.
- Attendance at a half day workshop “Effects of Divorce on Children”.
OLDER ADULT CORE PLACEMENT

Location: Pathfinder NHS Trust, Tooting  
Supervisor: Sara Turner

CLINICAL EXPERIENCE

Client Demographics
- 23 clients (19 female, 4 male) between the ages of 67 and 93 years.

Presenting Problems
- Depression
- Anxiety
- Chronic pain
- Dementia
- Stroke
- Bereavement
- Aggressive behaviour
- Dysphasia

Assessment Procedures
- Assessment interviews within a Cognitive Behavioural Framework
- Questionnaire assessments: Beck Depression and Anxiety Inventories, McGill Pain Questionnaire, Geriatric Depression Scale.
- Psychometric Assessments: CAPE, MEAMS, WAIS-R, WMS, RBMT, RPM,
- Observations and functional analysis
- Dementia Care Mapping

Interventions
- Cognitive Behavioural Therapy
- Life Review
- Carer Support
- Humanistic Counselling
- Cognitive Rehabilitation
- Behavioural Therapy
- Staff Training
- Anxiety Management Group (based on cognitive theory)

Other Work/Experience
- Case presentation to specialty Meeting.
- Attendance at multi-disciplinary meetings and specialty meetings.
- Observation of work of CPN, Psychiatrist and Social Worker.
- Attendance at Special Interest Group training day – “Neuropsychological Assessment of Older Adults”.
NEUROPSYCHOLOGY SPECIALIST
PLACEMENT

Location: Worthing Priority Care NHS Trust
Supervisor: Brenda Mumford

CLINICAL EXPERIENCE

Client Demographics

• 23 clients (7 females, 16 males) between the ages of 21 and 89 years.

Presenting Problems

• Memory difficulties.
• Multi-infarct dementia.
• Head injury.
• Alzheimer’s Disease.
• Illiteracy following childhood asphyxia.
• Encephalitis
• Cognitive deficits linked to chronic alcohol abuse
• Schizophrenia and cognitive deficits
• Query learning disabilities
• Anxiety
• Depression
• Anger

Psychometric Assessments Used

• NART – R
• WAIS-R
• AMIBP
• Wisconsin Card Sort Rest
• Verbal Fluency Test
• Warrington Recognition Memory Test
• Schonell Reading Test
• BADS
• Ravens Coloured Matrices
• MEAMS
• Rivermead Behavioural Memory Test

Interventions

• Anger Management
• Anxiety Management (CBT framework)
• Cognitive Rehabilitation
Other Work/Experience

- Attendance at Departmental Meetings, neurological multi-disciplinary meetings and Neuropsychological Special Interest Group meeting
- Attendance at a lecture on CT Scanning
PEDiatric psycho-oncology specialist placement

Location: Royal Marsden Hospital NHS Trust
Supervisor: Dr Lesley Edwards

clinical experience

Client demographics
• Placement not finished

Presenting problems
• Non-compliance with medication
• Treatment anxiety
• Family relationship difficulties
• Sibling jealousy
• Late effects post treatment - cognitive and social difficulties
• Depression
• Family anxiety
• Attachment problems
• Temper outbursts
• Eating problems
• Sleeping difficulties

Assessment procedures
• Assessment for therapy interviews.
• Behavioural Checklist
• Psychometric assessments: WISC-III, WPPSI-R, WRAML, WORD, and WOND.

Interventions
• Humanistic counselling
• Behavioural therapy/parenting skills
• Cognitive Behavioural and Cognitive Developmental Therapy
• Therapy within systemic framework
• Cognitive rehabilitation
• Liaison work

Other work/experience
• Attendance at departmental meetings and multi-disciplinary meetings.
• Lecturing on nursing diploma course and Youth Forum/Conference
CLINICAL CASE REPORT SUMMARIES
ADULT MENTAL HEALTH CASE REPORT

SUMMARY

Jackie: A case study of depression and adjustment disorder

March 1997

Year 1
Reason for Referral
Jackie (fictional name) was referred by the Consultant Psychiatrist because of persistent low mood, poor sleep, poor memory and suicidal ideations.

Assessment Procedure
The assessment involved a face to face interview and completion of the Beck Depression Inventory and the Personal Adjustment Questionnaire. The initial face to face interview followed a standard multi-modal assessment procedure; Jackie’s problems were assessed for physical, behavioural, cognitive, affective, interpersonal and drug influences. Questions concerning the onset, course, precipitating, modulation and maintaining factors for the problem were asked. Information concerning family background, personal history and current situation was also elicited and motivation, goals and expectations for therapy were established. The cognitive-behavioural model was explained with particular emphasis on the link between cognitions, affect and behaviour and the collaborative nature of working in therapy.

Formulation
Jackie presented with short temper, low mood, feelings of guilt and resentment in relation to life events, sleep problems, disturbing dreams, loss of interest in sex, lack of a sense of self, reduced level of activity, poor memory and concentration and negative intrusive thoughts about herself, particularly in relation to her body image. Relationships with her husband and two children were strained, because she believed that they did not understand her or what she was going through. Her Beck Depression Inventory score was 36. Using DSM-IV diagnostic criteria, Jackie was “diagnosed” as having Dysthymic Disorder and Adjustment Disorder with Depressed Mood.

Jackie’s current difficulties were precipitated by distal negative life events. The break up of her first marriage caused Jackie to feel rejected, angry and a failure. Following an emergency ileostomy operation in 1989, which left her with a permanent incontinent stoma, Jackie was left feeling embarrassed by her body. She felt imperfect and incomplete and hated herself. She did not want to have sexual relations with her
husband because of her stoma. Jackie also felt let down and angry with her surgeon because she believed that he had performed the operation without her consent.

Jackie’s current episode of depression was triggered by her dismissal from her job for stealing. She felt a failure and was ashamed and angry with herself. She had stopped going out in her loyal town, for fear of meeting one of her work colleagues or being recognised from the local paper article written about her. Jackie also felt let down and rejected by her employers and colleagues and believed that she had been unjustly punished for her actions. Jackie’s low mood was maintained by the negative thoughts she had about herself and her stoma and also by her symptoms of depression (low mood, avoidant behaviour, reduced activities, and poor sleep).

**Intervention**

Jackie attended 14, one-hour sessions of cognitive behavioural therapy. Jackie’s goals for therapy were; to reduce feelings of guilt and anger in relation to her dismissal from work, to feel able to get another job, to improve her sleep, and to be more appreciated.

CBT focussed on; monitoring, challenge and reducing negative automatic thoughts, reducing avoidant behaviour, exploring themes of rejection and tendency to take things personally, challenging unrealistic expectations of others, helping Jackie to express her needs to others, and helping to establish a better sleep routine.

**Outcome**

Jackie’s BDI score at termination of therapy was 9 indicating a substantial reduction in depressive symptomatology. She displayed less negative thinking and more insight into her problems. She reported to feel less angry about her job dismissal, and her relationships with her family improved. Her sleep was also improved. She went out more often and was thinking about applying for another job. She continued however to have difficulties accepting herself because of her ileostomy and found it hard to believe that she would be acceptable to others. She still reported finding it hard to express emotion to others because of her continuing fear of rejection.
People with Learning Disabilities
Clinical Case Report

Summary


September 1997

Year 1
**Reason for Referral**

Sam (fictional name) was referred to the Community Team for People with Learning Disabilities by his Social Services Care Manager, requesting assistance with his recent display of challenging behaviour. It was reported that Sam was pushing and knocking over other clients and members of staff in his Day Centre, throwing things such as chairs and dinners and occasionally urinating on himself.

**Background**

Sam was a 24 year old male with Down’s Syndrome and severe learning disability. He lived with his parents and two sisters. Sam also had a younger brother, also born with Down’s Syndrome but he died at the age of 8 (Sam was 10).

Sam was registered short-sighted and his hearing was impaired in his right ear. He did not have any verbal expressive language but was able to communicate using Makaton. His was able to understand simple questions and instructions.

Sam attended his local Day Centre on a full time basis, and attended Makaton classes, educational classes and art. He would not attempt to communicate or make friends with other clients. At home, Sam spent most of his time alone in his room watching childrens videos or looking at comics.

**Assessment of Challenging Behaviour**

The assessment and formulation of this case was based on social learning and operant conditioning theories.

Assessment of Sam’s challenging behaviour was carried out by 1) interviewing staff at Sam’s Day Centre, 2) requesting staff to complete Behavioural Record Forms, in order to be able to carry out a functional analysis of Sam’s problem behaviours, 3) two sessions of direct observation, 4) interviewing Sam’s mother, 5) reviewing the Community Team file.
Formulation
The functions of Sam's behaviour were hypothesised as; avoidance or escape from noisy and socially chaotic environments and social interactions, avoidance of close proximity; protection of personal space and belongings; avoidance of tasks. Sam's behaviour was suggestive of a disorder of social communication such as autism. His behaviour was maintained by the noisy and socially chaotic environment of the Day Centre and reinforced by the actions of staff when responding to his behaviour.

Intervention
A set of behavioural guidelines were devised and implemented, which consisted of 6 rules for managing Sam's behaviour. These guidelines intended to reduce the number of triggers to Sam's challenging behaviour (stimulus control), increase his means of communication and help staff respond to his challenging behaviour in a non-reinforcing manner. In addition, a positive reinforcement schedule was also implemented.

Assessment of Autism
Sam was assessed for autism by obtaining his developmental history, completing the Disability Assessment Schedule with Sam's mother and observing his behaviour.

His behavioural presentation since the age of 3 was indicative of a diagnosis of autism. As a result of this assessment information, additional recommendations were made for managing Sam more appropriately at the Day Centre, including predictable social interactions and routine, use of concrete language, increased personal space and a calmer environment.

Outcome
Staff at the Day Centre reported that Sam had responded well to the interventions. He appeared to value the reinforcements he received and displayed fewer episodes of the target behaviours. Staff also felt that Sam's diagnosis of autism helped them to better understand and manage his behaviour. Ideally, assessment of outcome would have been strengthened by the inclusion of additional sessions of direct observation and further analysis of behavioural recording forms.
CHILD AND ADOLESCENT CLINICAL CASE REPORT

SUMMARY

Treatment of Behavioural Difficulties using Family Therapy

March 1998

Year 2
Theoretical Framework

The formulation for this case was based on a number of theories within a Family Therapy framework, namely General Systems Theory, structural approaches and concepts underpinning the Milan approach to Family Therapy. Therapeutic intervention was based on Milan Systemic Family Therapy.

Referral

Matthew French (fictional name), aged 12, was referred to the Child Psychology Service by his GP, who detailed that Matthew’s father had visited her, with complaints regarding his sons verbally aggressive and disobedient behaviour at home. Matthew had also been badly bullied at school and had recently run away from home, to his Grandmothers. Mr French had admitted to becoming very angry at Matthew’s behaviour, shouting and smacking him and reacting to minor misdemeanours. The GP believed that Mr French had a depressive illness and prescribed him anti-depressant medication. Matthew was detailed as being the eldest of four children, having two sisters aged 9 and 5 and a brother aged 2.

The whole family was offered an appointment to be seen for an initial session of Family Therapy within the Child Clinical Psychology Service. Prior to the initial session, information from the referral letter was used to construct some initial working hypotheses to help guide questions for assessment.

The author was the lead clinician in all therapy sessions. The supervising Family Therapist remained behind a one way screen, using a telephone to communicate with the lead clinician during each session.

Systemic Formulation

Family Relationships

Mr French appeared distant and emotionally disengaged from both his wife and children. His relationship with his wife appeared to be characterised by conflict regarding the management of the children. Both parents exhibited differing beliefs about how the children should behaviour at home. This seemed to relate to them
adhering rigidly to opposing parental roles; Mr French acting as the children’s disciplinarian and Mrs French acting as the children’s mediator. Mrs French also appeared at times to have a rather disengaged relationship with her children, characterised by diffuse rules and chaotic behavioural control at home. Mrs French’s apparent inability or unwillingness to set consistent limits on her children’s behaviour, served to foster the process of re-engaging Mr French with his family, resulting in him taking more of a parental role. It appeared that Matthew’s way of getting close to his mother was to help and support her around the house. At times however, Matthew would take over the parental role from his mother, resulting in a symmetrical battle for power at home. Mr French formed an alliance with Matthew in relation to helping him deal with being bullied. Through a circular process, problems at school helped Matthew and his father develop a closer relationship.

Matthew appeared to be triangulated in a relationship with his parents. Mr and Mrs French united in seeking professional help in dealing with all their children, thereby seemingly using their children as scapegoats for avoiding their own marital conflicts.

**Symptom Formation**

Matthew’s behaviour at home appeared to communicate to both his parents that a renegotiation of his relationship with them was required. In particular, Matthew appeared to need his father’s support and guidance in managing his difficulties with bullying. The inflexible nature of the relationship between Mr French and his children, and his beliefs about managing their behaviour, appeared to make it difficult to renegotiate his relationship with his adolescent son. Matthew’s adolescence signalled the start for him to become more independent from his parents. This might have been a threat to the stability of the family system.

**Intervention- Four Sessions of Milan Family Therapy**

Using Milan philosophy, therapeutic change is achieved by introducing differences into a family. Change is triggered by the therapist introducing clarity to a confused or chaotic family system or by introducing different perspectives.
The four cornerstones of Milan methodology were systematically applied during this case; namely the use of circular questioning, pre-session hypothesising, neutrality and end of session interventions. End of session interventions were delivered in the form of a message or by using a reflexive team approach (between lead clinician and Family Therapist).

The presenting difficulties were re-constructed within the session in terms of the presenting problem behaviours, the meaning of those behaviours for different members of the family and its effects on relationships in the family system. The distant relationship between Matthew and his father was highlighted as possibly being associated with Matthew’s behaviour. It was identified that the process of transition in family relationships is often a difficult process to cope with and that the process of therapy appeared useful in helping the family to talk about relationship difficulties. It was suggested that the family try to find ways to continue the process of communicating outside of therapy.

**Outcome**

At the end of therapy, Matthew had moved schools and was feeling much happier. He reported to feel closer to his father because communication between them was improved.

Mr French had tried to help out at home with some of the household chores; this helped Mrs French to feel less tired and also helped Mr French to understand his wife’s daily lifestyle.

Mr French was trying to be more tolerant and understanding at home and Mrs French was trying to set firmer boundaries with the children (compromise). By session four, Matthew’s behaviour was not being constructed as a problem.

The evaluation of therapeutic change used subjective methodology and could have been strengthened by the use of objective measures such as questionnaires, rating scales or observational techniques.
Neuropsychological Assessment of a client with a history of alcohol use and depression

September 1998

Year 2
**Reason for Referral**

Mr West (fictional name) was referred to the Neuropsychology Service by his Psychiatrist at the local Community Mental Health Centre. He had been a moderate to heavy drinker for over 30 years, and also had a long history of severe depression with paranoia. The mental health team were concerned that this man had developed significant cognitive deficits as a result of his alcohol use, which might then have some bearing on planning his future management. A neuropsychological assessment was therefore requested.

**Background Information**

Mr West was a 62 year old man, who was divorced and lived alone in warden accommodation. He had three adult children, but had had no contact with them, or his ex-wife, for a number of years.

Mr West attended a secondary modern school and left at the age of 15, having obtained no academic qualifications. He spent all his working life in the building trade, mostly as a hod carrier. He stopped work in 1991 at the age of 55.

Mr West had been seeing a psychiatrist over the past 2 years for severe depression and paranoia. In 1997, Mr West received a 6 week course of ECT to treat his ongoing depression, however he refused any further ECT because of perceived short term memory problems. At the time of the current assessment, he was taking Prozac (20mg daily) and Sulpiride (120mg daily) medication.

Mr West reported a 40 year history of moderate to heavy alcohol consumption. During the 18 months prior to the current assessment he was drinking a bottle of whisky a day, but had reduced this to one bottle of whiskey every weekend, 6 weeks prior to the assessment.

**Working Hypotheses**

A number of working hypotheses were generated prior to assessment, in order to guide the assessment procedures. These included; localised organic damage as a result
of chronic alcohol abuse; Korsakoff's Syndrome, organic dementia; functional aetiology (cognitive effects of severe depression); acute effects of alcohol use, cognitive effects of ECT; and cognitive effects of prescription medication.

Neuropsychological Assessment
The New Adult Reading Test (NART) and the Wechsler Adult Intelligence Scales-Revised (WAIS-R) were used to determine pre-morbid and current levels of intellectual ability respectively. Straight verbal and visual memory and new learning were assessed using the Adult Memory and Information Processing Battery (AMIPB) and the Warrington Recognition Memory Test (RMT) was used to assess cued recall memory. A number of tests were used to assess frontal lobe functioning: the modified version of the Wisconsin Card Sort Test, The Controlled Oral Word Association Test and the "Draw a Bicycle" test. The Beck Depression Inventory (BDI) was used to obtain data on the severity of Mr West's reported depression.

Test Results
Despite a number of confounding variables, the overall results did reflect acquired mild generalised loss in cognitive functioning, which was more pronounced for performance skills than verbal skills. This, coupled with impaired visual memory compared with verbal memory was rather suggestive of something being more amiss with right hemisphere function than left. Mr West's pattern of cognitive deficits closely resembled the profile of deficits frequently seen in cases of chronic alcohol abuse. There was no evidence of severe memory dysfunction as found in people suffering from Korsakoff's syndrome. Functional aetiology (depression, anxiety) and acute alcohol intoxication, would tend to result in a mild fall off in cognitive skills but is unlikely to produce a hemispheric discrepancy in favour of right hemisphere functioning, as found in this man's cognitive profile. ECT is likely to effect memory for a short period after treatment, but does not have general effects on cognitive functioning as seen in Mr West test profile. Psychotropic drug use may cause deficits in performance skills but usually after several years of use. Mr West had only been taking medication for 2-3 years.
This man’s test profile was therefore suggestive of something *organically* amiss with cognitive functioning. However, strong conclusions as the underlying aetiology could not be made at this stage of testing. It was likely that Mr West’s cognitive deficits were a result of his long history of alcohol abuse. However, to diagnose whether he had a dementia, progressive deterioration would have to be established via neuropsychological re-testing at some time in the future (usually 12 months).
OLDER ADULT CLINICAL CASE REPORT

SUMMARY

A Case of Dementia and Challenging Behaviour

March 1999

Year 3
Referral

Ben Jackson (fictional name) was urgently referred to Psychology in January 1999, via the local “Community Mental Health Team for Older People”. The manager of Ben’s day care facility had originally contacted the Team’s psychiatrist because his staff were finding it increasingly difficult to manage Ben and cope with his challenging behaviour. It was reported that Ben was often verbally aggressive and on occasion, hit members of staff and other clients.

Background Information

Mr Jackson was a 67-year-old Jamaican born man who came to England when he was 15 years old to build a career. His uncle gave him a job as a welder and he remained a welder until the age of 60, when he retired as a result of ill health. He met his wife Vivienne when he first moved to England and they married 10 years later. They have two children, Daniel and Emma who both live at home with their parents.

Ben used to be an amateur boxer and enjoyed keeping fit at the gym. He used to play the trumpet and bass and liked listening to modern jazz and blues music. He also enjoyed playing cricket. His wife described him as a kind, dignified man and “a bit of a loner”.

Changes in Ben’s cognitive abilities were first noticed 6 years ago, soon after an operation to remove a kidney, which contained a malignant tumour. He continued to deteriorate in all areas of cognitive functioning and was eventually diagnosed with early onset dementia of probable vascular aetiology. At the time of assessment, Ben had marked expressive dysphasia and limited receptive language skills. He was able to engage for a short amount of time in social interaction, however his orientation and attention span appeared limited. He was fully ambulant and able to feed himself, however he needed some assistance with personal care such as dressing, washing and toileting. He was regularly incontinent of urine and on occasion, incontinent of faeces. Psychiatric examination found no evidence of any mental health disorder other than dementia.
**Assessment**

A holistic approach to the assessment of Ben’s presenting difficulties was carried out, using a “diagnostic” framework described by Stokes and Goudie (1990), which considers the influence of biogenic (physical health and handicap), psychogenic (personality and personal history) and environmental factors, on the behaviour of people with dementia.

An accurate assessment of the nature of Ben’s challenging behaviour was obtained by interviewing the team leader of the day centre and asking her to complete a Behaviour Problem Checklist. A functional analysis of his behaviour was carried out using information obtained from four sources; Behavioural Recording Charts, completed by staff at the Day Centre; two periods of direct observation; Interviews with the Day Centre Manager, Team Leader and various care staff at the Day Centre.

An assessment of Ben’s Day Care facility and quality of care was achieved within the framework of Kitwood’s theory of Dementia Care and Dementia Care Mapping.

**Formulation**

The following factors were seen to be contributing to Ben’s challenging behaviour; Marked difficulties with expressive and receptive language; Increased dependency on staff for personal care; Lack of therapeutic activities; Physical restrictions: Lack of “freedom”. Negative social interactions. The functions of Ben’s verbal and physically aggressive behaviour were hypothesised as; avoidance or reduction in demands made by staff; avoidance or escape from a noisy and socially chaotic environment and/or social interactions; avoidance of close proximity with other staff or clients. Protection of his personal space and dignity; attempts to control an environment, which seemed confusing and overcontrolling; attempts to communicate needs, wishes and feelings of anxiety, boredom, frustration and anger. Ben’s behaviour appeared to be maintained by his continuing experience of a negative physical and social environment and by the negative attitudes and behavioural responses of the staff at his day centre.
Interventions

Intervention was based on behavioural therapy and Kitwood's model of personhood which states that behavioural disturbances in people suffering from dementia, are best managed by increasing their relative well-being (self-esteem, power, social confidence, hope), through improvements in their social care environment.

Prior to the application of any behavioural intervention, Ben was prescribed a daily dose of Promazine by the Community Team psychiatrist.

Behavioural guidelines were devised to help the Day Centre staff communicate, respond and behave with Ben in more effective and appropriate ways. They suggested changes in ways of communicating with Ben, provided concrete suggestions for toileting and changing Ben and helping him onto the ambulance, provided ideas for increasing Ben's daytime activities; specifically using music and taking Ben for escorted walks and suggested ways of de-escalating Ben's aggressive behaviour when it occurred.

Due to initial problems with getting day care staff to implement the behavioural guidelines, a decision was taken to admit Ben to the local Day Hospital for two weeks in order to continue in-depth observation and assessment and provide a role model for staff at the Day Centre, to enhance their learning in managing Ben.

Outcome

Three days after Ben returned to the Day Centre, a serious episode occurred which involved Ben becoming physically aggressive towards a member of staff and being restrained. Discussions were initiated with the Local Health Authority, to negotiate terminating Ben's placement at the Day Centre and transferring him to the Day Hospital.

This case brought up a number of professional issues with regards to working effectively and successfully with staff groups.
SECTION THREE

RESEARCH DOSSIER
LITERATURE REVIEW

Family Factors in the Etiology and Maintenance of Chronic Pain

September 1997

Year 1
Introduction

According to Litman (1974), the family serves as the primary social context within which illness occurs and is resolved. Over the last three decades there has been an increase in the consideration of family factors in the etiology and maintenance of "psychosomatic" illness with an increase in the literature on the use of family interventions in the management of a wide range of "psychosomatic" and somatic illnesses. In the last 10 - 15 years there has been an increase in empirical evidence and theories to account for family factors in the etiology and maintenance of chronic pain (CP). However this is an area which is still relatively under-researched.

This review will critically discuss the evidence linking family factors to the development and maintenance of CP and review the theoretical models for explaining the links between CP and the family. Finding will be discussed in relation to suggestions for future research.

Associations Between CP And The Family

Family History of Pain

Research has shown high prevalence rates of pain or somatic complaints in families of children with CP. Apley (1975) found that children suffering from recurrent abdominal pain (RAP) were 6 times more likely to have a family member who suffered from recurrent pain, recurrent illness, pseudo-illness or psychological problems compared to a healthy control group. Christensen and Mortensen (1975) compared 46 children whose parents had current abdominal pain with 70 children whose parents reported no symptoms of pain. They found a significant different in reports of abdominal pain in children whose parents also reported pain. Robinson et al (1990) found a higher incidence of illness symptoms amongst parent's of children who presented to a paediatric clinic with RAP compared to children who presented to their GP with RAP. In comparison to a control group, both RAP groups showed higher parental incidence of migraine and elevated scores for hypochondriasis.
Many studies have also evidenced links between adult CP patients and prevalence of pain within their family of origin. Gentry et al (1974) found that 59% of their patients with lower back pain had close family members with lower back pain or some other debilitating disorder. They also found that 23% had a significant other who had chronic lower back pain. Blumer and Heilbrom (1981) found that 63% of their 234 patients reported having a family member or close friend with a chronic physical handicap or deformity. Merskey and Boyd (1978) found a high frequency of non-organic (idiopathic) pain in 12 patients whose mothers also had a psychosomatic illness. However all three of these studies failed to compare their results with a control group.

Merskey (1965) and Merskey and Spear (1967) compared two groups of psychiatric patients with and without complaints of CP and found a greater number of pain complaints expressed by parents or siblings of patients with CP. Similar prevalence rates were found by Skubiszewski (1981) and Violon and Guirgea (1984) who compared a group of 40 CP patients to a group of 50 patients with a chronic but pain free disease. They concluded that being exposed early to pain symptomatology may induce a somatic response to life stress.

Mohamed et al (1978) found that depressed patients with CP reported significantly more pain problems in their families, and spouses' families compared to a group of depressed patients without CP. They also reported a relationship between location of pain in their patients and location of pain in the patient's family member. This was also reported in a study by Turkat et al (1984) who found that headache patients had more family members who suffered from headaches than healthy controls. Hill and Blendis (1967) found that 52% of patients with non-organic abdominal pain reported that one or both parents had also suffered from abdominal pain compared to only 19% of patients with abdominal pain of known organic etiology.
**Family Structure**

A number of older studies have attempted to explore the links between family demographics (size, birth order, socio-economic status) and incidence of CP. However, research in this area has produced confounding results.

**Family Size**

Some studies have implied a connection between CP and a large family of origin (Gonda, 1962; Hill and Blendis, 1967). However, other studies have since lent evidence refuting this relationship (e.g.: Merskey and Spear, 1967; Sweeny and Fine, 1970). Furthermore Snelling (1990) concludes that the growing trend towards smaller families has decreased the likelihood of a strong connection between size of family and CP.

**Birth Order**

In 1935, Knopf reported that migraine sufferers were more likely to be the youngest or oldest sibling in the family and further concluded that pain may be used to obtain assistance or attention from parents or other siblings. However, Vernon (1974) found no relationship between birth order and pain experienced by children receiving injections. Further studies have also found no evidence for this hypothesis (Apley, 1975; Singer, 1977).

**Socio-economic status**

Merskey (1965) found that the pain patients in his study were more likely to come from blue collar backgrounds rather than from families of skilled workers. From this finding he suggested that working class people were more likely to interpret emotional pain physically rather than psychologically. However, other studies have failed to find differences in socio-economic status between pain and pain free controls (Gonda, 1962; Hill and Blendis, 1967; Violon and Giurgea, 1984; Martinez et al, 1995).
Loss of a Family Member

Loss of a family member through death or divorce has been linked to the development of "psychosomatic" disorders (e.g.: Fritz, 1985, Kelly, 1982). Damage to childhood health has been linked to the loss of a parent, especially before the age of 8 years (Brown, 1966, Cherlin, 1979).

Engel (1959) hypothesised that CP could be conceptualised as a somatic response to the loss of a significant interpersonal relationship. However, evidence to support this theory appears somewhat scare. Hill and Blendis, (1967) found that a significant number of their 19 adults with non-organic pain associated the onset of their symptoms with the death of a parent. Hughes (1984) found in his study of 23 children with abdominal pain, that their families were often preoccupied with the loss or threatened loss of grandparents. However, the researchers did not report any baseline data showing levels of preoccupation of loss in families with symptom free children. Robinson et al (1990) used the Children’s Life Events Inventory and found a significant relationship between abdominal pain and prevalence of stressful events in the 12 months directly preceding the onset of symptoms. Events concerning childhood interpersonal relationships such as parental divorce or separation were particularly involved. They concluded that stressful events may act as important triggers for the development of pain in susceptible individuals.

Not all studies support the link between parental loss and CP. Merskey (1965) found no significant difference between psychiatric patients with pain and pain free controls with regard to the number who had lost a parent before the age of 15. In addition, research as yet is unable to disentangle the influences of divorce or separation on the development of CP from other related factors such as marital conflict or the changing nature of the parent-child relationship.

Early Parent-Child Relationship

In addition to loss of a parent during childhood, a number of descriptive studies have stressed the important of the parent-child interaction in the subsequent development of CP. Parental rejection and abandonment of the child have frequently been linked to the
etiology of psychosomatic disorders including CP (e.g.: Bowlby, 1980; Joffe and Vaughn, 1982). Engel's (1959) famous description of the “pain-prone” personality, includes a history of an unhappy childhood involving physical and emotional abuse. Other descriptive studies have supported this assertion. Hudgens (1979) reported that 10 of his 24 patients with CP described their parents as harsh, demanding or distant. Violon (1980), reports 92% of patients with cluster headaches and 80% of patients with atypical facial neuralgia as having a history of early affective deprivation which included battering and abandonment. Gross et al (1980/81) reported that 80% of their patients with pelvic pain had a lack of maternal warmth and a history of passive-dependent relationships in their family. In a more controlled study, Merskey and Boyd (1978) found that 6 of their 70 patients with non-organic pain had rejecting fathers and 4 had punishing mothers. No such relationships were reported from any of the 71 patients with organically based pain. However, this study was of retrospective design, using self report data. The reported numbers were small and no pain free control group was used to establish a baseline for childhood interactions in the general population.

A number of studies have looked at patterns of parental interaction with children who have CP. Hughes (1984) and Hughes and Zimin (1978) observed the interactions of families who had a child with non-organically based pain. Family relationships were described as problematic. The mother was often anxious and critical and failed to recognise and attend to the basic emotional needs of their children. This study however, failed to compare results to a suitable control group. The observed patterns of familial interactions may have been a result of stress relating to having a child with CP, rather than being an etiological factor. Grunau et al (1994) found that maternal involvement was significantly related to a greater level of somatization in a group of preterm infants. Maternal sensitivity to cues from the children was significantly related to lower somatization. The authors went on the suggest that mother-child interaction may be an important mediating factor in coping with pain, as opposed to an etiological factor. There was no mention of the influence of paternal interactions.
Most of the studies in this area have been descriptive or retrospective in nature, with the absence of comparable control groups. In one of the only studies to use a control group, Robinson et al (1990) found little significance of the mother-child relationship between children with recurrent abdominal pain and pain free controls.

**Family Functioning**

In 1974, Meissner described families of ‘psychosomatic’ patients as rigid and emotionally repressed. Minuchin (1978) proposed a conceptual model of the ‘psychosomatic’ family which included 4 main characteristics; enmeshment, overprotectiveness, rigidity and lack of conflict resolution. Similar characteristics have been described in clinical studies examining the functions of families of patients with CP. For example, Liebman (1976) described the families of children with RAP as having weak boundaries, ineffective divided parents, little autonomy and privacy, rigid systems and an incapacity to resolve conflict. Payne (1982) rated 47 families entering a multidisciplinary pain centre and found that the majority exhibited poor communication, rigid family roles, patient dependency and spousal reinforcement of pain behaviours. Similar characteristics were reported in a study by Norfleet et al (1982) in their ratings of ‘pain couples’. Feuerstein et al (1985) compared 33 CP patients with healthy controls on the Family Environment Scale (FES; Moos and Moos, 1981). They reported higher scores for family conflict and control in chronic lower back pain patients.

In a more recent study, Kopp et al (1995) attempted to examine the differences in family functioning for different types of CP. They examined the characteristics of 36 families, 12 in which the mother had chronic headache, 12 in which the mother had chronic lower back pain and 12 pain free controls. Using the Family Climate Scale (Cierpka, 1988), they found that there was a reduced level of intra-familial expressiveness in families with a member suffering from chronic headache compared to the other two groups. Headache families also showed a marked degree of organisation which was equated to Minuchin’s description of psychosomatic families as being inflexible and rigid. They concluded that in headache families there is less openness in expressing feelings, less spontaneity and less room for unsanctioned expression of
criticism or annoyance. However they point out that causal relationships can not be established from the results. The observed family functioning could be an adaptation to coping with a family member with CP.

Not all studies have produced equivocal results. Nicassio and Radojevic (1993), examined 44 patients with rheumatoid arthritis and 46 patients with Fibromyalgia (chronic muscle pain). They found that both pain groups tended to describe their families as being generally supportive, low in conflict and high in independence. They conclude that their findings do not converge with stereotypic notions of 'psychosomatic' families as described by Minuchin. Wasserman et al (1988) and Sanders et al (1990) found no differences in family functioning as measured by the FES, between families with children with RAP and matched controls. Walker et al (1993) compared RAP, peptic ulcer and control families on 3 subscales of the FES and found no difference in family functioning between the three groups. Differences in research methodology between studies concerning family functioning and pain may be one explanation for the unequivocal findings in this area.

Marital Relationships

A number of studies have found an association between CP and prevalence of pain in patients spouses'. Mohamed et al (1978) found that spouses' of patients with CP had a high prevalence of pain problems compared to spouses of patients with depression. They also found that there were more pain problems found in the spouses family. They suggested that pain patients might select spouses with similar psychological profiles or problems. Shanfield et al (1979) made the same conclusion in their study which found a significant correlation in symptom severity scores, as measured by the SCL-90, between pain patients and their spouses. They also suggested that an increase in spousal symptomatology could be a reaction to marital difficulties or the difficulty of living with a partner with CP. Flor et al (1987) reported more pain complaints in spouses of CP patients as compared to diabetic patients.
Research has also found an association between CP and spousal interaction. Romano et al (1992) found a greater tendency on the part of spouses of CP patients to respond to their partners pain with solicitous behaviour compared to control subjects. In turn, pain patients were more likely to respond to spouses solicitous behaviours with pain behaviours than control subjects. They concluded that a spouses solicitous behaviour acts as a positive reinforcer for pain behaviour and is therefore a maintaining factor for CP. Similar results were found by Flor et al (1987), Anderson and Kehm (1984), and Block et al, (1980) who found that patients with solicitous spouses reported a marginally higher level of pain than nonsolicitous spouses. They concluded that CP patients may systematically alter the report of their level of pain depending on their perception of spousal response to pain behaviours.

Other studies report an association between CP and poor marital and sexual relationships. Merskey and Boyd (1978) found that CP patients with no known organic lesions had marriages characterised by upsets, blows, conflicting interests or separations compared to a group of CP patients with organic lesions. Maruta et al (1981) found that chronic pain patients reported a deterioration in marital relationships and a decrease in the frequency of sexual activity after the onset of pain. Payne (1982) interviewed 47 couples in a treatment program at a multidisciplinary pain centre and found that 91% reported sexual problems and decline in their social lives.

Family History of Depression

A limited number of studies have looked at family history of depression in CP sufferers. Blumer and Heilbrohn (1981) found preliminary data suggesting that pain prone disorders tend to occur in patients with alcoholic family members or family members who suffer from unipolar depressive disorders. Schaffer et al (1980) found that 86% of their clinically depressed pain patients had a positive family history of depression. They suggested that these patients were themselves suffering from a primary affective disorder. Krishnan et al (1985) also found similar results. Their clinically depressed pain patients reported a history of depression and a higher percentage of first degree relatives with affective disorders, compared to the pain
patients without major depression. *Hudson et al (1992)*, compared 31 patients with fibromyalgia with 14 patients with rheumatoid arthritis. They found that both the rate of major affective disorder (MAD) and familial history of MAD were significantly higher in the fibromyalgia patients.

Researchers have suggested that CP is either a somatic representation of major depression (e.g.: *Magni and DeBertolini, 1983*), or that pain and depression share common characteristics (*McCreary and Turner, 1984*). Others have proposed that CP represents an emotion in its own right (e.g.: *Swanson, 1984*) and may either be precipitated by depression or that depression may act to lower pain sensitivity thresholds (e.g.: *Romano, 1985*).

Methodological difficulties lead us to be cautious about inferring that depression plays a role in the etiology of CP. The majority of the empirical studies are retrospective in nature and rely on self report methods for data collection. Mood affects memory (*Bower, 1981*) and the presence of depression may distort the memories of the patients on which these results heavily rely. It is difficult to establish whether the presence of a CP patient in the family unit precipitates or is precipitated by depression in other family members.

**Theories Of Etiology And Maintenance Of Chronic Pain**

**Role of genetics**

The etiology of CP has been linked to genetic factors and inherited hypersensitivity to pain. For example, *Devor et al (1982)* and *Inbal et al (1980)* demonstrated that it was possible to genetically engineer high and low pain sensitive rats. *Apley (1975)* reported a frequent association between abdominal pain and autonomic dysfunction's in patients and their families and suggested a possible role for genetic factors. *Bille (1981)* followed up children with migraines into adulthood and assessed the incidence of migraine in their children. 46% of female migraine sufferers were found to have
children with migraine compared to 11% of male sufferers. He suggested that a predisposition to CP might be inherited through female genes.

Not all studies have supported the idea that hereditary factors play an important role in the etiology of CP. Christensen and Mortensen (1975) failed to find an elevated frequency of abdominal pain among children of parents who had suffered for RAP during childhood. Only children of parents who were currently complaining appeared more subject to pain. They concluded that pain was not hereditary but developed through processes of early learning. Limited research coupled with methodological difficulties in studying the subjective experience of pain currently makes it impossible to know the level of influence genetic factors might have in determining subsequent development of pain.

Psychodynamic View

Engel (1959) believed that early childhood experiences influenced the development of a “pain-prone” personality. A pain prone personality was characterised by a number of intrapsychic factors such as predominance of guilt and a strong aggressive drive, and interpersonal factors such as childhood suffering and family history of aggressive and hostile relationships. Engel believed that CP was triggered by a real or threatened loss.

More recent psychoanalytic case descriptions of CP patients have focused more on salient interpersonal aspects. Blumer and Heilbrohn (1982) viewed the development of CP as the somatic expression of unresolved psychic conflict stemming from early childhood experiences such as a family history of depression, alcoholism and abuse. They concluded that CP was best viewed as a depressive-spectrum disorder.

Other researchers have conceptualised that pain proneness develops in childhood, specifically as a result of unfulfilled dependency needs. These unfulfilled needs are associated with unempathic parenting and a chaotic early family history. CP develops as an interaction between physical injury and the primitive expression of those dependency needs (Van Houdenhove, 1986).
Within the psychodynamic framework for the etiology of CP, the importance of contextual factors such as early family functioning are recognised, however, they still remain secondary to predisposing intrapsychic factors. Empirical support is given, in part, by studies linking the prevalence of early aversive experiences and dysfunctional parent-child relationships in adult patients with CP. These studies however, have not identified the existence of intrapsychic factors or the degree of influence they may have in interaction with contextual factors and processes of social learning.

**Attachment Theory**

*Mikail and Henderson (1994)*, present a working model for the etiology of CP based on Bowlby’s attachment theory. According to Bowlby, infant attachment is a function of genetically based behaviours. Attachment behaviour serves to protect the individual throughout the lifecycle when faced with threats (*Ainsworth and Bowlby 1991*). An infant’s early experiences with attachment figures (caretakers), is internalised and forms a working model upon which later relationships are based. The early experience of responses given in the face of threat serves to establish a set of expectancies for responses by others in later life. Therefore an individual whose attachment behaviours were repeatedly frustrated in infancy will come to anticipate rejection, abandonment and a lack of empathy. These expectations may trigger a response of avoidance and hostility, which in turn elicits the expected response from others (*Ricks, 1985*).

According to *Mikail and Henderson (1994)* CP develops from a dynamic interaction between three systems; biological, intrapsychic and external or systemic. Biological alterations such as tissue damage serves to precipitate the pain experience. Intrapsychic and systemic factors serve as vulnerability factors for CP. Intrapsychic factors include self schema’s, characteristic patterns of coping and an internal working model developed from early attachment experiences. External or systemic variables include familial environments, responses to illness and interpersonal interactions.
The specificity of a syndrome or condition (e.g.: location of pain), is determined by the unique combination of a given biological change occurring within the context of a particular intrapsychic structure and the associated social context (Mikail and Henderson, 1994).

As with the psychodynamic view, it would appear that early parent-child interactions are an important influence for the etiology of CP. Family beliefs and responses to illness behaviour are important factors in the perpetuation of the pain experience.

This theory offers an interesting framework for the development and maintenance of CP. The working model appears similar to a biopsychosocial model, with an emphasis on specific intrapsychic development. As yet, no studies have specifically tested the theory in relation to the development of CP. Mikail and Henderson offer a few suggestions for future research including examining the prevalence of early attachment styles in CP sufferers, and examining the relationship between attachment style and interpersonal functioning.

**Family Systems Model**

There are a number of different theories that can be classified as being a family systems model as they share a number of common features. The family is viewed as a system of networks of relationships, with the functioning of each member in part dependent on the functioning of the other members. The main function of the family as a whole is the maintenance of homeostasis within the family unit (Payne and Norfleet, 1986). According to this model, any chronic symptom that develops is believed to serve a stabilising role in the family system.

According to Turks conceptualisation (Turk et al, 1987), each individual uses their family to establish a separate identify. If family interactions or functioning prevents this from occurring in childhood, the individual becomes undifferentiated, and lacks independence from the family. Maintenance of family attachments, dependency and reductions in emotional conflict is achieved either through assuming a sick role or maintaining it in another family member.
According to Patterson’s Family Adjustment and Adaptation Response model (FARR, Patterson, 1988, 89), the family attempts to maintain homeostasis by employing its resources for coping with the stress associated with chronic illness. The family’s cognitive appraisal of the demands of an illness and its coping capacities will influence its functioning. This model has been commended for emphasising the importance of cognitive appraisal within the family in comparison to other family systems models, however, there is a lack of empirical research to support its conceptions.

Evidence for the family systems model of CP, comes from research into early child-parent interactions (as related to unresolved childhood conflicts) and descriptive studies of common family characteristics of CP patients, including, emotional over involvement, enmeshment, collusion and inability to resolve conflict. However, the family systems model has been criticised for using vague idiosyncratic concepts that are difficult to operationalise, observe and empirically evaluate.

**Social Learning Theory**

Bandura (1977) has demonstrated that observational learning is one of the major modes of acquiring new behaviours. Children acquire attitudes and perceptions of appropriate responses to injury and disease from their parents and social environment. Children particularly observe how other family members respond to pain because it is a key symptom in many injuries and illnesses. Families will tend to reinforce pain behaviour by giving attention and sympathy and taking over the responsibilities for the “sick” family member. Children who are witness to prolonged, intense or frequent pain and illness in a family member may become predisposed to unusual patterns of pain complaint themselves (Craig, 1978). This may be particularly true for a child who has observed their family member being positively reinforced for pain behaviours (Craig, 1980). This model seems to account for the high incidence of pain occurring in families. A number of studies support the observational learning theory for the acquisition of CP. Christensen and Mortensen (1975) found that children were more likely to have the same pain symptoms as their parents at the present time. They were
less likely to have the same pain their parents had when they were children. *Edwards (1985)* found a correlation between reports of intermittent pain and number of familial pain models in their population of 288 college students. *Richard (1988)* reported that children of CP patients chose more pain related responses to scenarios presented to them and were external in their health locus of control than were children with healthy or diabetic parents. Moreover, teachers also reported observing more pain behaviours in the children of CP parents compared to healthy controls.

Physiological responses associated with pain may also be transmitted from parents to children by means of vicarious or observational learning. *Block (1981)* reports that spouses of CP patients respond with heightened physiological arousal when viewing their patient spouse in pain. However, arousal alone does not account for the experience of pain. Cognitive factors are likely to act as contributing factors in the process of pain perception.

This learning model alone does not seem an adequately explanation for the etiology of CP. Many children will experience models of pain and reinforcement of pain behaviours, yet not develop CP later in life. Observational learning through exposure to pain models may act as a necessary predisposing factor, but may not be sufficient for the subsequent development of CP.

**Operant Conditioning Model**

Early in life, children progressively learn how to behave, by the reactions their behaviour generates (*Craig, 1980*). Children are likely to repeat the behaviours that are followed by enjoyable results or avoid disagreeable consequences. The learning of pain behaviours is perceived to occur early in an individual's life (see section above) and used operantly in adult life (*Fordyce et al, 1985*). According to the operant formulation of CP, an individual who is exposed to tissue damage, may produce a number of learnt behaviours to avoid or reduce acute pain. These may include reducing activities or seeking help from others to reduce the symptoms. These behaviours are observable and open to learning. Acute pain behaviours may be
reinforced (by significant others) and subsequently develop into a chronic pain condition. The operant model is therefore less concerned with the initial cause of pain but focuses more on explaining the processes of maintenance.

The main support for this theory comes from research on the association between spousal reactions and the prevalence of pain behaviours in CP patients (e.g.: Turk et al, 1992, Romano, 1992). Treatment of CP using operant methods have also proved successful, where the focus has been on the extinction of pain behaviours and positive reinforcement of well behaviours (e.g.: Keefe et al, 1992).

The operant theory for CP has its limitations. The majority of the population is likely to have experienced acute pain at some time in their life's and been given sympathy, attention and support during the experience. Yet, a minority will develop non-organic CP. This suggests that other factors (emotional, cognitive, systemic) are somehow involved. Operant treatments have also been criticised for failing to address the subjective experience of pain.

**Cognitive-Behavioural Theory**

Cognitive schema's, beliefs and attitudes are thought to have a strong influence on the development and maintenance of CP. Schema's are used by the individual to determine the meaning and significance of the world in which he/she lives. Schema’s incorporate a network of underlying beliefs by which we perceive, analyse and interpret behaviour, sensation, affect etc.

Families are thought to be a main influence on the development of schema’s early in an individual's life. In particular, families influence beliefs about illness, pain, disability and emotional and behavioural responding to illness and pain. This is achieved via the families psychological reactions to illness and subsequent reinforcement of coping strategies or maladaptive behaviour.
Much research has examined the significance of cognitive factors in subjective pain and disability (e.g.: Jensen et al, 1991; Turk and Rudy, 1992). However, little empirical evidence has looked at the association of “family” cognitions and CP. Most evidence has concentrated on exploring the operant formulation.

Conclusions

There are a number of weaknesses inherent in the methodological approaches of studies in this area:

- Most of the research evaluates the occurrence of CP in the family using retrospective self-report measures. Self-report measures are open to memory and perceptual biases. Retrospective studies are unable to establish causal relationships between the family and etiology of CP.

- The inadequate use of control groups and lack of non-standardised assessment instruments are identified by Turk et al (1987) as methodological problems hampering interpretation of research data.

- Some studies have examined non-behavioural variables (e.g.: enmeshment, collusion) that are difficult to operationalise and therefore difficult to objectively evaluate and interpret.

- Most studies have studied CP as a global condition or have studied patients with specific pain localisations. This makes it difficult to generalise conclusions across all pain conditions.

Despite these methodological problems it is still possible to make some tentative conclusions. It appears that there is a tendency for pain patients to come from families which include a member suffering from chronic pain and/or a depressive illness. Evidence linking family factors to the etiology of CP appears to be less abundant or conclusive than evidence linking family factors to the maintenance of CP. It is conceivable that pain behaviours are maintained through reinforcement by spouses and/or other family members and may indeed serve to maintain familial homeostasis as proposed by the family systems model. Cognitive factors such as familial health and
illness beliefs, may influence an individual's predisposition for developing CP. Chronic pain is very likely to have an effect on the functioning of the family through the disruption of parental, marital and sibling relationships, familial roles and increased levels of emotional distress.

There appears to be a need for a greater amount of methodologically sound empirical research in this area. Particularly here is a need for prospective studies to establish causal links between family factors and CP. More studies need to examine the extent of familial influences in the development of attitudes and beliefs about pain and differences between pain localisations. Finally, the theoretical models and conceptualisations developed within this specific area could be tested further by applying them to chronic illnesses similar to CP, such as Chronic Fatigue Syndrome.


SMALL SCALE RESEARCH
(INCORPORATING SERVICE RELATED RESEARCH)

Staff Attitude Change Towards People With Learning Disabilities Subsequent To Training: An Empirical Study

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Year 2
1 ABSTRACT

A review of the literature suggests staff attitudes and behaviour can positively or negatively affect service provision and the quality of life for people with a learning disability. Training which addresses staff attitudes and behaviours, has been found to improve staff job performance and subsequent provision of care for this client group. This study uses a quasi-experimental research design to evaluate a series of workshops, designed to bring about staff attitudinal change (n=205) towards people with a learning disability. A likert scale attitude questionnaire, was used to collect data “before and after” the workshop and at three months following workshop attendance. Attitude change was evaluated across all three measurement periods and for staff exhibiting extreme attitudes. A comparison of attitude change was made between a) staff of differing ages and gender, from different professional groups, with differing work experience and levels of contact, and b) staff with differing attitudes towards their work environment and motivation for training. Findings suggest that attitudes held by the total sample towards people with learning disabilities were very positive. Training appeared to have a greater impact on moderating extreme positive attitudes and the attitudes of unqualified care staff. Methodological limitations, which question the reliability of the conclusions made, are discussed at length. Recommendations for methodological improvements and future research are made.
2 INTRODUCTION

Staff attitudes and behaviour can positively or negatively effect service provision and client care, and it is for these reasons that a number of important research studies have explored attitudes of health and care staff towards people with a learning disability. Staff attitudes can be influenced by a number of interacting factors including staff characteristics and experiences, and staff training. Training which addresses staff attitudes and behaviours, can result in improvements in staff job performance, which in turn, is likely to influence the provision of care and improve the quality of life of service users. There is increasing pressure to produce research based evidence for the success of training programmes, due to increasing demands for training within the constraints of small training budgets.

2.1 PRINCIPLES OF CARE THAT HAVE INFORMED ATTITUDES

A number of care philosophies have provided the basis from which services for people with learning disabilities have developed, both in the NHS and in the voluntary and private sectors. These philosophies have also helped to inform attitudes towards people with learning disabilities. Some of the most influential philosophies of care include, consumerism (Mooney, 1990), the principle of autonomy (Haber, 1985), the Human Rights movement (e.g.: Osmanczyk, 1985), care in the community (1990) and the concept of quality of life (Brown et al, 1989). To date, the most influential philosophy of care for people with learning disabilities particularly in relation to informing staff attitudes and values, appears to be the concept of Normalisation (Wolfensberger, 1975).

2.2 NORMALISATION

The original concept of Normalisation, developed by Wolf Wolfensberger (1972,1980), sought to promote the quality of life for people with learning disabilities by emphasising their rights to lead the most culturally normal lives as possible. Early definitions of Normalisation became a way of guiding services to reflect the basic

The original concept of Normalisation was criticised for being frequently misinterpreted and misapplied in relation to providing services for people with learning disabilities (Barr, 1995). As a result, in 1983, Wolfensberger reformulated and renamed his theory “Social Role Valorisation” (SRV) which stressed that the goal of Normalisation was the acquisition of valued roles in society for all people at risk of social devaluation. The theory assumed that the acquisition of valued roles would automatically bring about all the other elements and objectives of Normalisation, such as image and competency enhancement, positive status and reputations, positive identities and culturally valued lives (Elks, 1994) However, the concept of SRV has not been widely accepted (Emerson, 1992). Elks, (1994) states that the term SRV is not a valid or acceptable replacement for Normalisation. He argues that SRV emphasises the importance of valuing a person’s role in society and de-emphasises the importance of valuing people as individuals. This distinction is not found in the original concept. He also argues that valued social roles do not automatically lead to culturally valued lives and identities as proposed by Wolfensberger. In practice, the introduction of SVR appears to have confused the concept of Normalisation. Some professionals have viewed SVR as a new philosophy rather than being an “improvement” on the original concept (Barr, 1995).

In the UK, John O’Brien re-interpreted Wolfensberger’s original concept of Normalisation into five accomplishments which he felt services should try to put into practice for users (O’Brien 1987). These are classified and defined as:

- **Community Presence;** “the sharing of the ordinary places that define community life”
- **Choice;** “the experience of autonomy both in small, everyday matters (e.g.. what to eat or what to wear) and in large, life-defining matters (e.g.. with whom to live or what sort of work to do)”
• *Competence*: "the opportunity to perform functional and meaningful activities with whatever level or type of assistance that is required"

• *Respect*: "having a valued place among a network of people and valued roles in community life"

• *Community Participation*: "the experience of being part of a growing network of personal relationships that includes close friends"

Normalisation and O'Brien's five accomplishments have provided a widely utilised framework for the development of current and future services for people with learning disabilities. Normalisation has encouraged more forward thinking in care philosophies within institutions and has advocated greater community integration (Hughson and Brown, 1992) and de-institutionalisation (Wolfensberger, 1972, 1995).

### 2.2.1 Critique of Normalisation

Although Normalisation has become a central concept in many services, its background theory and practical implementation have been extensively criticised over the years. Wolfensberger has been viewed as overly idealistic (Brown & Smith 1992), and the theory has been denounced for being ambiguous and non-specific in relation to a post-institution approach for care (Briton 1979). Chappell (1992) believes that normalisation reflects the views of professionals, rather than the actual experiences and aspirations of those with a learning disability, and that it fails to examine the power relationship between these two groups.

Professionals have argued that principles of Normalisation can be misinterpreted or adhered to in an unquestioning and inflexible manner. Szivos (1991) argued that Normalisation denies the special needs of people with learning disabilities which can result in their *de*-valuation and repression though a lack of appreciation by others, of their differences in relation to the normal population. This is reiterated by Gilbert (1993) who argues that Normalisation is essentially a professional philosophy that treats people with learning disabilities as a homogenous group and fails to account for their uniqueness. Wolfensberger (1995) himself, argues that the misapplication of
Normalisation or SVR stems from the wrongful interpretation of probabilistic statements in the theory, as absolutistic. From this, stems the development of extreme attitudes, which may be just as harmful as those which de-value people with learning disabilities.

Whilst the majority of criticisms directed at Normalisation appear valid, many focus on common misinterpretations rather than the original principle itself. Wolfensberger’s theory recognises that people with learning disabilities need specialist resources as they go through the process of Normalisation and increasing independence (Wolfensberger 1972). Despite all it’s problems, the philosophy of Normalisation still remains a significant influence on the care of people with learning disabilities.

2.3 ATTITUDES OF PROFESSIONALS WORKING WITH PEOPLE WITH LEARNING DISABILITIES

Staff attitudes and behaviour can positively or negatively effect service provision and client care (Burgio, Whitman & Reid 1983, Mansell 1995, Fitzsimmons and Barr, 1997). It is for these reasons that a number of important research studies have explored attitudes of health and care staff towards client groups such as those with a mental illness or learning disability. *(For a more in-depth review see Fitzsimmons and Barr, 1997).*

2.3.1 The Definition and Measurement of Attitudes

Atkinson et al (1990) defines attitudes as

“likes and dislikes - affinities for or aversions to objects, persons, groups, situations or any other identifiable aspects of the environment, including abstract ideas and social policies”

Attitudes are comprised of three components; affective, cognitive and behavioural. The affective component is shown by the expression of either positive or negative emotion towards people, objects or situations. The cognitive component is ideas-
formed about people, objects or situations. The behavioural component is the tendency to behave in a particular way towards people objects or situations which is determined by the affective and cognitive components (Breckler, 1984: cited in Slevin and Sines, 1996).

When a strong positive or negative attitude is held towards a particular group, without supporting evidence or in the face of contradictory evidence, it becomes known as a prejudice. Rigid, biased attitudes about a person or groups' characteristics become stereotypic attitudes.

Attitudes can be measured using written scales (Fitzsimmons and Barr, 1997) or through the use of interviews. Attitude questionnaires usually comprise a series of statements relating to the specific attitude(s) of interest. Respondents are required to rate their level of agreement to each statement on a binomial or ordinal scale. Attitude questionnaires assume that attitudes can be captured verbally and analysed quantifiably. They also assume that attitude statements will be interpreted in the same way by all respondents. Tests of reliability and validity are used to enhance the objectivity and utility of the questionnaire. Questionnaires are an attractive tool of measurement as they are quick to administer and analyse. However, they constrain information on attitudes, by limiting the statements they use to measure them.

Attitudes can also be captured using less structured measurement techniques such as interviews. Interviews can produce a greater amount and depth of knowledge about an individuals attitudes, through the use of more open ended questions. However, they are time consuming both to administer and to analyse, and are vulnerable to response and interviewer bias (Schweigert, 1994). Due to time constraints, most research studies measuring attitudes, tend to use scientifically established or specifically developed attitude scales.
2.3.2 Previous Research

The most studied professional population for investigating attitudes towards people with a learning disability have been qualified and student nurses. (Fitzsimmons and Barr, 1997).

Barr (1990) found that student nurses had inaccurate knowledge of people with a learning disability and underestimated their abilities and problems. However, in general, the majority of attitudes expressed were positive (within the concept of Normalisation). Murray and Chambers (1991) found that prior to their learning disabled placements, student nurses had more favourable attitudes towards the elderly population or those with a physical disability than those with a learning disability. After their placements, their attitudes had improved. Fewer nurses agreed that it was up to the government to take care of people who are disabled and that there should be special institutions for them. More nurses agreed that it would be best for learning disabled people to live in residential homes. In a more recent study, Slevin and Sines (1996) used a modified version of the “Attitude Towards Disabled Persons” scale (ATDP: Yuker et al, 1966) and semi-structured interviews, to measure the attitudes of 31 qualified and unqualified nurses towards people with learning disabilities. Graduate nurses were found to be more positive in their perceptions compared to non-graduate nurses but attitudes held by the total sample were more negative than would be expected from those in a caring profession. 31% of nurses referred to people with learning disabilities as “totally different”, having poor expectations and “bizarre behaviour”. 47% expressed fears of violence by people with learning disabilities. 70% felt that a nurse for people with learning disabilities should remain with the person when they come into general hospital and 31% felt they should be nursed in a side room away from the general ward.

A number of other studies have investigated the attitudes of different health care professionals towards people with a learning disability (e.g.: Wolraich, 1987; 1993; Harris and Brady, 1995). In a study investigating the attitudes of paediatricians towards people with a learning disability, Wolraich et al (1987), found that paediatricians differentiated the capacities and eventual residential and vocational placement of learning disabled individuals with different levels of severity. They were
also restrictive in their expectations of the capabilities of severely disabled individuals. Wolraich et al concluded that paediatricians held more negative attitudes than other doctors working with this client group, as measured in a previous study (Wolraich and Siperstein, 1983). Given the importance of some life and death decisions made by paediatricians in relation to disabled children, Fitzsimmons and Barr (1997) rightly suggest in their review, that negative attitudes in this professional group must warrant further investigation. Harris and Brady (1995), explored the attitudes of speech and language therapist (SLT) to intimate relationships among people with learning disabilities. Results indicated relatively favourable attitudes towards someone with a mild disability having an intimate relationship, but less favourable toward someone with a severe disability having an intimate relationship. It could not be concluded from the study that the unfavourable attitudes were directly related to the intimate relationship rather than to another confounding factor such as independent living.

2.4 INFLUENCES ON STAFF ATTITUDES

Attitudes are influenced by a number of interacting factors including staff characteristics and experiences, and staff training.

2.4.1 Staff Characteristics

Research findings of the relationship between staff characteristics and attitudes towards people with learning disabilities, have so far been inconclusive.

Slevin (1995), and Beckwith and Mathews (1995), found that female staff were more likely to have positive attitudes towards people with a learning disability than male staff. However, in their studies on student nurses, Whitby (1986) and Slevin, (1995), failed to find a significant differences in attitudes between males and females.

Slevin (1995), and Slevin and Sines (1996) found that staff with higher levels of contact with learning disabled populations were more positive in their attitudes compared to those with little or no contact. Barr, (1990) and Whitby, (1986), failed
to find a significant correlation between level of staff contact and attitudes. Further research is needed to explore in more detail the nature and duration of the staff contact and relationship to attitudes (Barr and Fitzsimmons, 1997).

Slevin and Sines (1996) and Antonak (1995) report that levels of education can effect staff attitudes. However, Barr, (1990) Slevin, (1995) and Whitby, (1986) all failed to establish the existence of any relationship between staff levels of educational attainment and their attitudes towards service users. Again, more research is needed to explore the influence of such factors as the content of information and duration of education received by staff (Barr and Fitzsimmons, 1997).

2.4.2 Training
A number of research studies have shown a change in staff attitudes and behaviour toward service users following training. Training which addresses staff attitudes and behaviours, can result in improvements in staff job performance (Landesman-Dwyer & Knowles, 1987) which in turn, is likely to influence the provision of care and improve the quality of life of service users (Smalley, Certo & Goetz, 1997; Landesman-Dwyer & Knowles, 1987).

2.4.2.1 Evaluating The Effects Of Training
Gorman (1991) defines training as;

"a structured means by which people learn new skills, and knowledge which enables them to be more proficient in their jobs"

He argues that the evaluation of training has two purposes: to prove that worthwhile activity is taking place; and to improve the quality of the activity. There is increasing pressure to produce evidence for the success of training programmes due to increasing demands for training within the constraints of small training budgets (Gorman, 1991). Despite this, many organisations, including the NHS, fail to evaluate rigorously the effectiveness of training.
Much of the research methodology for the evaluation of training has been informed by the literature on commercial management and educational training programmes (Newman & Milne 1993, Garavaglia, 1993; Bramley, 1996). Many methods for the evaluation of training have traditionally been based on a model by Kirkpatrick (1959), which proposes that training objectives should be set and assessed for four levels;

- reactions of trainees to the programme
- learning of principles, facts skills and attitudes
- behavioural change in the job
- results: changes in criteria of organisational effectiveness

(Cited in Bramley, 1996 and Garavaglia, 1993)

A number of studies (Bramley, 1996, Garavaglia, 1993; Easterby-Smith & Tanton, 1985) have criticised the many organisations which only measure at the reaction level and use ‘end of session’ questionnaires or response sheets to record participants opinions. They argue that such evaluations are biased and are habitually not used in productive ways subsequent to collecting the data.

Other models have proposed frameworks for training evaluation. Gorman (1991) argues that a “competence-based approach” offers organisations, individual learners, and training providers a systematic method of identifying training needs and assessing the effect of training. A competence is defined as the ability to perform in work roles and jobs to the standards required in employment. Competencies offer a link between the needs of the organisation, the human workforce and specific requirements of training to meet organisational needs. Evaluation is targeted to investigate whether training can subsequently be applied consistently in the workplace as evidenced by the attainment of specific job competencies. In relation to the NHS, Gorman argues that more rigorous evaluation, from a competence-based approach, will provide the means for NHS services to become more “integrated and dynamic” rather than “fragmented and ineffective” Rigorous evaluation may require the use of a variety of types of evaluation, which collect data from multiple sources and at different time periods. Garavaglia (1993) suggests a number of different evaluation methods including.
quantitative (questionnaires) and qualitative (interviews) approaches. The "competence approach" requires organisations to be precise about what competency actually means, which in practice may not always be easy to achieve, particularly in relation to less objective concepts such as attitudes towards people with learning disabilities.

In relation to staff working in residential settings for people with learning disabilities, Landesman-Dwyer and Knowles (1987) developed an ecological framework on which a thorough evaluation of the effects of staff training could be based. Ecological assessment of staff training means evaluating staff performance within its naturally occurring contexts. Their model involves five basic assumptions about staff-environment relations:

- Staff behaviour is influenced by the behaviour and expectations of others in the work environment.
- The behavioural style, skills, attitudes and personal preferences of staff members influence the environment in which they work.
- Staff attitudes and behaviour are amenable to change and must be measured on multiple occasions to provide a valid evaluation
- Staff training represents an important medium for promoting change in staff attitudes and behaviour, which in turn may the environment in which they work.
- Staff behaviour directly influences the quality of life for people with learning disabilities.

(Adapted from Landesman-Dwyer and Knowles, 1987)

From this model, Landesman-Dwyer and Knowles propose that to study the effects of a particular staff training programme, a contextual evaluation of staff performance needs to be conducted prior to implementing the training. A contextual evaluation involves a baseline description of the social ecology of the residential environment as well as the characteristics of the staff and effects of the training programme itself. This would involve measuring aspects of;
• staff activity
• staff communication
• body language
• emotional expression
• with whom staff interact
• who initiates social exchange
• nature of stereotypic behaviour

A number of standardised tools have been developed to help assess the nature of environments (e.g.: PASS-3, Wolfensberger and Glenn, 1975; Caldwell Home Observation for Measurement of the Environment (HOME), Bradley and Caldwell, 1977). However, these tools do not correlate well with each other and many are now out of date in light of de-institutionalisation and the NHS reforms. Landesman-Dwyer and Knowles propose that data be gathered from multiple perspectives using a number of measurement techniques. In practice, a thorough analysis of the working environments of staff undergoing training is likely to be costly and time consuming and therefore an unattractive procedure to undertake for an evaluation study.

2.4.2.2 Short-Term Vs. Long-Term Effects Of Training
Findings like Newstrom’s (in Garavaglia 1993) that 40% of skills are immediately transferred after training, but only 25% remain after six months, suggest the importance of evaluating short-term and long-term effects of training. Garavaglia argues that follow-up evaluation assessments after a number of months are important in order to show whether any immediate changes have been sustained whilst on the job. Landesman-Dwyer and Knowles (1987) propose not only that short-term training effects are different to long-term effects, but that they are influenced by different factors. The immediate effects of training are seen to be dependent more on the format and relevance of the training content, as opposed to the longer term effects which are more dependent on the density of trained staff (number of staff who share the same skills and knowledge) and whether the goals of training are supported by the environment that the staff work in.
2.4.2.3 Effects of Training

A number of studies have been published on the effects of training on staff working with people with learning disabilities.

In their study of behaviour modification training for staff working in 12 group homes, Schinke & Wong (1977) found that immediately after training, staff had significantly more knowledge of behavioural techniques, had better evaluations of their residents and indicated less decline in job satisfaction compared to a non trained control group home. Allen, Pahl & Quine (1990) reported significant differences in areas such as job satisfaction, positive attitudes towards residents and community based services, between qualified hospital staff who had undergone in-service training and those who had not.

Rose and Holmes (1991), evaluated the effect of two workshops designed to change the attitudes and behaviour of staff towards the sexuality of people with learning disabilities. The two workshops differed in duration, one day and three days respectively. After both workshops, staff expressed attitudes that they would be more willing than before to assist their residents in making informed sexual choices. The three day workshop produced a greater shift in attitudes compared to the one day workshop.

Binney (1992), found that the attitudes and skills of qualified and student nurses, in running activity groups for people with profound learning disabilities were significantly improved, following a one day workshop focusing on this issue. Nursing assistants failed to show post training skill improvement.

McDonnell, (1997) evaluated the effect of a 3-day staff training course in the management of challenging behaviour. 21 staff were assessed for increased knowledge, self confidence and performance in managing challenging behaviour. Results showed that training did increase knowledge and skills but had the most significant effect on staff level of confidence. The study had no measure of whether
the effect of the training generalised to the workplace. No control group was used and no follow up data was collected to enable an analysis of the longer term effects of training.

Smalley et al (1997), evaluated the effectiveness of training programme, designed to enhance staff knowledge around challenging behaviours, valued activities, physical and social integration for adults with severe disabilities. Five participants took part in the training and all showed marked increases in their clients valued activities, social and physical community integration. Causal explanations were cautiously made due to limitations in the design methodology of the study.

Riding (1997), reported the results of an empirical evaluation of the impact of an “Exploring Values” workshop, on staff attitudes towards people with a learning disability. He found that staff attendance on the workshop was successful in bringing about positive attitudinal change. However, Riding highlighted a number of methodological problems with his study. Firstly, mean attitude scores were derived for each of the 16 workshops, as opposed to individual scores. Data was lost on those individuals who may have experienced a negative shift in attitudes. In addition, an evaluation of different attitude shifts for staff with predominantly either very positive or negative attitudes could not be made using mean attitude scores. Riding did not have the time or capacity to report any long term effects of the workshop, or to evaluate attitude change in relation to the different areas measured.

The current research project will attempt to address some of the methodological problems in Riding’s study, by using a longitudinal quasi-experimental design to evaluate a series of workshops designed to bring about staff attitudinal change towards people with a learning disability.
3 BACKGROUND AND RATIONALE FOR THE PROJECT

Hospital management at St Ebbas, Epsom, a long stay institution for people with learning disabilities, commissioned a private sector training company to run the same "Exploring Values" workshop as that evaluated by Riding (1997). St Ebbas is one of a few remaining long stay institutions for people with learning disabilities in the South East of England. 341 residents are cared for by 21 individually managed homes, located within the hospital grounds. Four homes are delegated to care for those residents with moderate to severe challenging behaviour, and 9 homes care for those with both physical and learning disabilities. Additionally there are two day service units and a number of therapy departments on site (psychology, speech and language, art and drama therapy).

3.1 RATIONALE

Staff resources were allocated by hospital management, to evaluate the effectiveness of the workshop, in relation to staff attitudes subsequent to training. The rationale for developing the current study was to ensure that attendance at the workshop was an efficient use of staff time and had some effect on improving the quality of care given to hospital residents.

3.2 LARGER STUDY

The current study forms part of a larger project, too extensive to be reported here, involving a number of investigators. In relation to the study described below, this author (VH) was responsible for:

i. taking a lead role in the design of the large scale project and also in the procedure and methods of the study reported below.

ii. designing the questionnaire used in this study.

iii. independently analysing and interpreting the data presented in this study, which was gathered by an assistant psychologist (HSP).
4 AIMS AND HYPOTHESES

4.1 AIM

The aim of the current study was to evaluate whether training changed staff attitudes towards people with learning disabilities.

4.2 HYPOTHESES

Based on theoretical deductions and past findings relating to this area of research; the following hypotheses were proposed for this study:

1: Attendance at an "Exploring Values" workshop will moderate extreme positive or negative attitudes held by staff towards people with a learning disability ($H_1$).
2: Staff attitude change towards people with a learning disability will be maintained over a 3-month period ($H_2$).
3: Staff characteristics will influence staff attitude change towards people with a learning disability subsequent to training ($H_3$).
4: Staff attitudes towards their working environment and their motivation for training will influence attitude change towards people with a learning disability, subsequent to training ($H_4$).

5 METHODS

5.1 DESIGN

A longitudinal quasi-experimental approach (no control group) was designed to provide quantitative data regarding staff attitudes pre, post and 3 months following attendance at an "Exploring Values" workshop.

5.1.1 Description of "Exploring Values" Workshop.

Twelve 2-day workshops were commissioned to be run over the course of a year, with compulsory attendance for all residential and day services staff. Every workshop was
run by the same facilitator to ensure consistency of training. The aims and objectives of the workshops are detailed in Appendix I, and include topics covering attitudes towards learning disabled people, health care issues (day one) teamwork, managing care, therapeutic interventions and service development (day two).

5.1.2 *Techniques for Attitude Change*

As part of exploring and changing staff attitudes towards their residents, part of each workshop was dedicated to working through the "Lifestyles for People with Mental Handicaps" pack (East Sussex Consultancy and Training Agency, 1985).

The “Lifestyles for People with Mental Handicaps” pack consists of a number of statements relating to personal and social options, such as relationships, privacy, freedom of choice etc. Each workshop participant was given one of these statements, and invited to sort it under one of three categories: “Things I value for myself”, “Things I don’t value for myself” and “Don’t mind”. When all participants had completed this task, the group as a whole was encouraged to consider each statement in relation to the choices available for people with learning disabilities. A facilitated discussion then developed from the dissonance between staff values and the values of residents in their care. It was not the intention of this exercise to get all participants to think and act towards their residents as though they were “normal” people. The exercise was intended to help participants value their residents whilst maintaining a sense of the unique and special needs of the client group with which they work. This included facilitating discussions about issues such as constricting the right to choice and privacy for known dangerous and violent individuals.

5.1.3 *Dependent and Independent Variables.*

The workshop was hypothesised to have an effect on participant attitudes towards people with learning disabilities. Therefore the workshop was regarded as being the independent variable and participant attitudes were regarded as the dependent variable.
In addition, a number of staff demographic variables and specific staff attitudes towards the work environment and motivation for training, were hypothesised to have interacting effects on attitude change. These were therefore regarded as unmanipulated independent variables (Table 1)

**TABLE 1: UNMANIPULATED INDEPENDENT VARIABLES**

<table>
<thead>
<tr>
<th>Independent Variables</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographic variables:</td>
</tr>
<tr>
<td>• Age</td>
</tr>
<tr>
<td>• Gender</td>
</tr>
<tr>
<td>• Professional Group</td>
</tr>
<tr>
<td>• Time Worked With Learning Disabled People</td>
</tr>
<tr>
<td>• Experience In Community Vs Institutional Settings</td>
</tr>
<tr>
<td>• Experience Of Having A Disabled Relative</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Staff Attitudes</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Job Satisfaction</td>
</tr>
<tr>
<td>• Individual Contribution To Care (work efficacy)</td>
</tr>
<tr>
<td>• Motivation For Training</td>
</tr>
<tr>
<td>• Team Work</td>
</tr>
<tr>
<td>• Job Roles</td>
</tr>
</tbody>
</table>

5.2 *PARTICIPANTS*

205 hospital staff, of mixed age, gender and job types (Table 5: results section), attended 11 workshops during a 12 month period. 205 and 197 staff completed pre-workshop and post-workshop questionnaires respectively. 181 staff completed questionnaires 3 months after attending the workshop (8 members of staff had left their posts within the follow up period). 177 staff completed all three stages of the evaluation.
5.3 MEASURES

It was decided that the use of a pre-established questionnaire such as the Attitude Towards Disabled Persons (ATDP) scale, should not be used within the current study. The ATDP has been the most widely utilised measure in the evaluation of staff attitudes and the effects of training on staff attitudes, and has established good reliability and validity. However, it is not designed to capture extreme "positive" attitudes towards people with a learning disability, i.e.: attitudes which reflect the misinterpretation of the principle of Normalisation, and denies the special needs of people with learning disabilities. In order to measure the effects of training on extreme (either positive or negative) staff attitudes, a questionnaire was specifically designed for this study. (Appendix II)

Twelve questions, in the form of statements, were devised to measure attitudes towards people with learning disabilities within the framework of O'Brien's five service accomplishments (community presence, choice, community participation, respect/valued, competence). Six attitude statements were worded to reflect extreme normalisation of people with learning disabilities, and 6 attitude statements were worded to reflect extreme devaluation of people with learning disabilities. Respondents were required to rate their level of agreement for each statement, on a six point likert scale, where 1 was strongly disagree and 6 was strongly agree. (Table 2).
TABLE 2: ATTITUDE STATEMENTS USED IN THE STUDY

<table>
<thead>
<tr>
<th>Extreme Positive (Normalising) Attitude Statements</th>
<th>Scale</th>
<th>O'Brien’s Accomplishments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Residents should be involved in all decisions regarding their care</td>
<td>123456</td>
<td>CHOICE</td>
</tr>
<tr>
<td>It is essential for staff to always provide residents with privacy</td>
<td>123456</td>
<td>RESPECT</td>
</tr>
<tr>
<td>It is our duty to accommodate our residents every wish</td>
<td>123456</td>
<td>VALUES</td>
</tr>
<tr>
<td>All people with LD can be taught to be independent</td>
<td>123456</td>
<td>COMPETENCE</td>
</tr>
<tr>
<td>It is best for people with LD to only have non-disabled friends</td>
<td>123456</td>
<td>COMMUNITY PARTICIPATION</td>
</tr>
<tr>
<td>All residents should have access to public recreation facilities</td>
<td>123456</td>
<td>COMMUNITY PRESENCE</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Extreme Negative (Devaluing) Attitude Statements</th>
<th>Scale</th>
<th>O'Brien’s Accomplishments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Residents should not be given choice about where they live</td>
<td>123456</td>
<td>CHOICE</td>
</tr>
<tr>
<td>People with LD do not have the same emotions as non disabled people</td>
<td>123456</td>
<td>RESPECT</td>
</tr>
<tr>
<td>Punishment is sometimes the only way of controlling the behaviour of people with LD</td>
<td>123456</td>
<td>VALUES</td>
</tr>
<tr>
<td>Little can be done to help severely handicapped residents to improve</td>
<td>123456</td>
<td>COMPETENCE</td>
</tr>
<tr>
<td>Residents are better off only making friends with other residents</td>
<td>123456</td>
<td>COMMUNITY PARTICIPATION</td>
</tr>
<tr>
<td>It is beneficial for people with LD to have separate facilities from the general population</td>
<td>123456</td>
<td>COMMUNITY PRESENCE</td>
</tr>
</tbody>
</table>

The remaining 14 items on the questionnaire, were devised to measure staff attitudes towards their working environment (job satisfaction, job roles, work efficacy, views on teamwork) and motivation for training. Each question was in the form of a statement to which respondents were asked to rate their level of agreement on a six point likert scale (Table 3).
TABLE 3: ITEMS DEvised TO MEASURE STAFF ATTITUDES TOWARDS THEIR WORK ENVIRONMENT AND MOTIVATION FOR TRAINING.

<table>
<thead>
<tr>
<th>Questions</th>
<th>Scale</th>
<th>Measuring</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am very happy with the physical condition of my work place</td>
<td>123556</td>
<td>JOB SATISFACTION</td>
</tr>
<tr>
<td>There are many tasks in my job that I do not enjoy doing</td>
<td>123556</td>
<td>JOB SATISFACTION</td>
</tr>
<tr>
<td>I am not happy with the shifts I work</td>
<td>123556</td>
<td>JOB SATISFACTION</td>
</tr>
<tr>
<td>There is little opportunity for me to develop my career</td>
<td>123556</td>
<td>JOB SATISFACTION</td>
</tr>
<tr>
<td>It is a vital part of my job to assist with residents therapy programmes</td>
<td>123556</td>
<td>JOB ROLES</td>
</tr>
<tr>
<td>My job is to contain residents challenging behaviour, not to change it</td>
<td>123556</td>
<td>JOB ROLES</td>
</tr>
<tr>
<td>I feel that the work I do has little impact on improving the lives of the residents</td>
<td>123556</td>
<td>WORK EFFICACY</td>
</tr>
<tr>
<td>My individual approach to residents can make an important contribution in their care</td>
<td>123556</td>
<td>WORK EFFICACY</td>
</tr>
<tr>
<td>Staff team work is not essential for giving residents good care</td>
<td>123556</td>
<td>VIEWS ON TEAMWORK</td>
</tr>
<tr>
<td>I work in an efficient staff team</td>
<td>123556</td>
<td>VIEWS ON TEAMWORK</td>
</tr>
<tr>
<td>This workshop will not tell me anything new</td>
<td>123556</td>
<td>MOTIVATION FOR TRAINING</td>
</tr>
<tr>
<td>This workshop will change the way I view people with LD</td>
<td>123556</td>
<td>MOTIVATION FOR TRAINING</td>
</tr>
</tbody>
</table>

Due to time constraints in devising a reliable alternative form of the questionnaire, the same pool of questions were used to measure attitudes at pre and post workshop and 3
months follow up. The pre-workshop and follow up questionnaires were identical and the questions were reordered for the post-workshop questionnaire. (Appendix II)

5.3.1 Pilot Study

The author participated in the first workshop prior to the start of evaluation, and piloted the pre and post workshop questionnaires on 20 staff participants. This resulted in some vital changes to the questionnaire prior to the start of the main study. The devised attitude statements were adjusted, so that they became more strongly worded, either positively or negatively, in order to better evaluate extreme staff attitudes.

5.3.2 Demographic Details

Questions were also devised to collect demographic details for each participant on the workshop (Table 4).

**TABLE 4: DEMOGRAPHIC QUESTIONS USED IN THE STUDY**

<table>
<thead>
<tr>
<th>Name: ........................................</th>
<th>Gender: M........ F........</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age: ......................................</td>
<td>Job title:..........................</td>
</tr>
<tr>
<td>Which home do you work on:................</td>
<td>..................................................</td>
</tr>
<tr>
<td>Length of time worked with people with learning disabilities (LD):...............</td>
<td></td>
</tr>
<tr>
<td>Length of time worked in St. Ebba’s:........................................</td>
<td></td>
</tr>
<tr>
<td>Have you ever worked with people with LD in the community?:..................</td>
<td></td>
</tr>
<tr>
<td>Do you have any relatives with a learning disability?:..........................</td>
<td></td>
</tr>
</tbody>
</table>
5.4 PROCEDURE

Staff were given an information sheet detailing the aims and methods of the evaluation study (Appendix III). Each participant was asked to give their demographic details and complete a pre-workshop questionnaire, prior to attending the training workshop. Participants were then required to complete a post-workshop questionnaire immediately after completing the workshop and at 3 months follow up.

6 STATISTICAL ANALYSES

All data was analysed using the Statistics Package for the Social Sciences (SPSS) version 6. Descriptive and summary statistics were obtained for all dependent and independent variables. Cronbach inter item reliability analyses (Tabachnick and Fidell, 1996) were performed on all pre, post and follow up questionnaire items, designed to measure attitudes towards service users.

Non parametric, independent samples statistics (Kruskal Wallis 1 way ANOVA’s, Mann - Whitney U Tests and Spearman correlation’s) were performed to analyse pre-workshop attitudes and attitude change in relation to staff demographic variables. Non parametric, related samples statistics (Friedman 2 way ANOVA, Wilcoxon) were used to analyse attitude change across the three measurement periods (Schweigert, 1994; Coolican, 1990; Norusis, 1993).
7 RESULTS

7.1 SCORING AND RELIABILITY OF THE QUESTIONNAIRE

7.1.1 Scoring
Negatively worded questionnaire items were recoded, in order that high scores would indicate more positive attitudes and low scores would indicate more negative attitudes. A mean of 3.5 was considered to represent liberal, realistic attitudes towards people with learning disabilities.

7.1.2 Reliability Analyses
An Inter-item reliability test, using the Cronbach's Alpha statistic (Tabachnick and Fidell, 1996) was performed upon the 12 items in the questionnaire, devised to measure attitudes towards those with a learning disability. For the pre-workshop questionnaire, three questions (Q3, 12 and 19) were found to lower the inter item correlation of the attitude scale below an acceptable standard of reliability (below 0.6 alpha coefficient). When these three questions were excluded, a reliable Cronbach alpha coefficient of 0.65 was achieved for the remaining 9 item attitude scale. This same scale, produced an alpha coefficient of 0.66 on the post-workshop questionnaire and 0.69 at 3 months follow up, indicating adequate inter-item correlation at all three stages of data collection. Because the reliability score was fairly low, a more stringent significance level of 0.01 was used to reduce the chance of making any type two errors.

7.2 STAFF CHARACTERISTICS
205 members of staff (84% day staff and 16% night staff) attended 11, 2-day workshops over the course of a year (average of 19 staff per workshop). Demographic details of the participating staff are shown in Table 5. In general the majority of staff attending the workshops were unqualified care workers (50%) and qualified nurses.
(27%), with more than 10 years experience (mean number of years worked in LD = 11).

**TABLE 5: DEMOGRAPHIC DETAILS OF PARTICIPATING STAFF**

<table>
<thead>
<tr>
<th>Participant Demographics</th>
<th>N*</th>
<th>Means, Percentages and Frequencies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender Distribution</td>
<td>205</td>
<td>43% Males</td>
</tr>
<tr>
<td></td>
<td></td>
<td>57% Females</td>
</tr>
<tr>
<td>Mean Age</td>
<td>162</td>
<td>36 (Range: 18-60 years)</td>
</tr>
<tr>
<td>Job Titles</td>
<td>204</td>
<td>101 (50%) Unqualified care workers</td>
</tr>
<tr>
<td></td>
<td></td>
<td>60 (29%) Qualified nurses</td>
</tr>
<tr>
<td></td>
<td></td>
<td>9 (4%) Psychologists</td>
</tr>
<tr>
<td></td>
<td></td>
<td>16 (8%) Instructors</td>
</tr>
<tr>
<td></td>
<td></td>
<td>18 (9%) Home managers</td>
</tr>
<tr>
<td>Mean No. Of Years Worked In</td>
<td>193</td>
<td>11 (range: 1 month - 40 years)</td>
</tr>
<tr>
<td>Learning Disabilities.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean No. Of Years Worked In</td>
<td>195</td>
<td>8 (range: 1 month - 34 years)</td>
</tr>
<tr>
<td>St Ebbas</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Worked in the community</td>
<td>197</td>
<td>25% Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>75% No</td>
</tr>
<tr>
<td>Relatives with LD</td>
<td>196</td>
<td>10% Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>90% No</td>
</tr>
</tbody>
</table>

* Variable N’s due to missing questionnaire data.

7.3 **PRE-WORKSHOP ATTITUDES TOWARDS PEOPLE WITH LEARNING DISABILITIES.**

Pre-workshop mean attitude scores and standard deviations for the total sample and sub-groups of the sample are detailed in Table 6. Positive attitudes towards people
with learning disabilities, were exhibited by the majority of staff prior to workshop attendance (mean = 5.07: where 1 = extreme negative/devaluing attitudes and 6 = extreme positive/valuing attitudes). A significant difference in mean attitude scores were found between different professional staff groups (Kruskal Wallis 1 Way ANOVA; \( \chi^2 = 28.50 \) (4 df), \( p < 0.0001 \)). Mann Whitney U analyses found that Home Managers (U= 360.5, \( p < 0.0001 \)) and Qualified Nurses (U= 1837.0, \( p < 0.0001 \)) had significantly higher mean attitude scores (i.e. more positive / normalising attitudes towards people with learning disabilities) than unqualified care workers.

**TABLE 6: PRE-WORKSHOP MEAN ATTITUDE SCORES AND STANDARD DEVIATIONS**

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Mean attitude score</th>
<th>SD</th>
<th>( P )</th>
<th>df</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total sample</td>
<td>205</td>
<td>5.07</td>
<td>0.69</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unqualified Care Worker</td>
<td>101</td>
<td>4.84</td>
<td>0.68</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychologists</td>
<td>9</td>
<td>4.99</td>
<td>0.57</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Instructors</td>
<td>16</td>
<td>5.04</td>
<td>0.79</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Qualified Nurses</td>
<td>60</td>
<td>5.32</td>
<td>0.59</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home Managers</td>
<td>18</td>
<td>5.56</td>
<td>0.55</td>
<td>( p &lt; 0.0001 )* 4</td>
<td></td>
</tr>
<tr>
<td>Males</td>
<td>90</td>
<td>4.97</td>
<td>0.72</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Females</td>
<td>115</td>
<td>5.15</td>
<td>0.66</td>
<td>( p = 0.0640 ) 1</td>
<td></td>
</tr>
<tr>
<td>Worked in the Community</td>
<td>49</td>
<td>5.19</td>
<td>0.67</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not worked in the community</td>
<td>148</td>
<td>5.02</td>
<td>0.70</td>
<td>( p = 0.1706 ) 1</td>
<td></td>
</tr>
<tr>
<td>Relative(s) with LD</td>
<td>19</td>
<td>5.30</td>
<td>0.55</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No Relative(s) with LD</td>
<td>177</td>
<td>5.04</td>
<td>0.70</td>
<td>( p = 0.1389 ) 1</td>
<td></td>
</tr>
</tbody>
</table>

* Significant \( p \) value (Kruskal Wallis 1 Way ANOVA)
A significant correlation was found between staff attitudes and number of years worked with people with learning disabilities (Spearman's correlation; $r_s = 0.2494 \ p < .001$). Staff who had worked longer in learning disabilities generally showed more positive valuing attitudes.

Mann Whitney U analyses found no statistically significant differences in pre-workshop mean attitude scores between male and female staff ($U = 4396, \ p > 0.01$), staff who had vs had not previously worked in a community setting ($U = 3153, \ p > 0.01$) and staff who did vs did not have a relative(s) with a learning disability ($U = 1335, \ p > 0.01$). There was no relationship found between mean attitude scores and participants age (Spearman correlation; $r_s = -0.01, \ p > 0.01$).

### 7.4 ATTITUDE CHANGE TOWARDS PEOPLE WITH LEARNING DISABILITIES

Mean attitude scores and standard deviations for all three measurement periods are detailed in Table 7.

**TABLE 7: MEAN ATTITUDE SCORES AND STANDARD DEVIATION FOR ALL THREE MEASUREMENT PERIODS.**

<table>
<thead>
<tr>
<th></th>
<th>Pre-workshop</th>
<th>Post-workshop</th>
<th>3 months follow up</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
<td>Mean</td>
</tr>
<tr>
<td>Total Sample</td>
<td>5.07 (0.69)</td>
<td>5.14 (0.68)</td>
<td>4.86 (0.78)</td>
</tr>
<tr>
<td>Top 25% of staff with the highest pre-workshop attitude scores</td>
<td>5.91 (0.10)</td>
<td>5.72 (0.25)</td>
<td>5.12 (0.88)</td>
</tr>
<tr>
<td>Top 25% of staff with the lowest pre-workshop attitude scores</td>
<td>4.21 (0.43)</td>
<td>4.41 (0.79)</td>
<td>4.65 (0.64)</td>
</tr>
</tbody>
</table>
There was a significant change in mean attitude scores from pre-workshop to 3 months follow up (Friedman 2 Way ANOVA; $\chi^2 = 14.12$ (n=176; 4 df), $p<0.001$). Attitudes were slightly but not significantly more positive immediately after workshop attendance (Wilcoxon; $Z = -1.8011$, $p > 0.01$), however general attitudes were significantly less positive at 3 months follow up, compared to both pre workshop attitudes ($Z= 2.9131$, $p<0.01$) and post workshop attitudes ($Z = 4.4871$, $p < 0.0001$). Staff attitudes towards people with learning disabilities at follow up were still highly positive (mean = 4.86, sd=0.78).

Quartile values for pre-workshop mean attitude scores were calculated in order to identify the top 25% of participants, who had the highest and lowest attitude scores. Friedman 2 way ANOVA’s and Wilcoxon analyses were used to explore attitude change post workshop and at follow up, for these two participant groups. Means and standard deviations for these groups are detailed in table 7.

Significant attitude change occurred for both groups, following workshop attendance. (Friedman 2 Way ANOVA; i) most positive staff group $\chi^2 = 48.83$ (n=46, 2 df, $p < 0.0001$: ii) least positive staff group, $\chi^2 = 17.28$ (n = 48, 2 df, $p < 0.001$).

Participants who exhibited the most positive/normalising attitudes towards service users before attending the workshop, exhibited significantly less positive views post workshop (Wilcoxon $Z = 4.6690$, $P < 0.0001$). At 3 months follow up, mean attitude scores were significantly less positive than at post - workshop attitudes (Wilcoxon: $Z = 4.4013$, $P < 0.0001$: Figure 1).

Participants who exhibited the least positive/normalising attitudes towards people with learning disabilities before attending the workshop, exhibited significantly more positive views post workshop (Wilcoxon: $Z = 4.3118$, $p < 0.0001$). These changes in attitudes were significantly maintained at 3 months follow up (Wilcoxon: $Z =2.8947$, $p< 0.01$: Figure 1)
FIGURE 1: Changes In Mean Attitude Scores For Staff Groups With The Highest (=> 75th Quartile) And Lowest (<= 25th Quartile) Pre-Workshop Mean Attitude Scores.

7.5 STAFF CHARACTERISTICS AND ATTITUDE CHANGE

Changes in mean attitude scores were calculated for each individual subject by:

i) subtracting pre-workshop mean scores from post-workshop mean scores.

ii) subtracting post-workshop mean scores from follow up mean scores.

The mean attitude change from pre-workshop to post-workshop was 0.43 (0.44 sd).
The mean attitude change from post workshop to follow up was -0.63 (0.64 sd).

7.5.1 Staff demographic variables and attitude change

Scores of mean attitude change (as above) were used in a series of Mann-Whitney U tests, Spearman correlation’s and a Kruskal Wallis One Way ANOVA to compare attitude change in relation to a number of staff characteristics. Attitude changes from pre-workshop to post-workshop and follow up were not significantly associated with
any staff demographic variables (see Appendix IV). However, there was a non-significant trend towards unqualified care workers having the largest change in attitudes and Instructors having the smallest change in attitudes, immediately after workshop attendance (Kruskal-Wallis One Way ANOVA; \( \chi^2 = 12.36 \), (n=196, 4df) \( p = 0.015 \)).

7.5.2 Staff Attitudes Towards Their Work Environment, Motivation For Training and Attitude Change.

A series of Spearman correlation's were performed between scores of mean attitude change and scores on individual questionnaire items relating to staff attitudes towards the work environment and motivation for training (see Appendix V). There was a small but statistically significant negative correlation between mean attitude change scores, post-workshop and staff attitudes towards their role in assisting therapeutic programmes (\( r_s = -0.19 \) (n=194) \( p<0.01 \)). Staff who rated that a vital part of their job involved assisting therapeutic programmes, exhibited less attitude change, compared to staff who did not rate that their job involved assisting in therapeutic programmes. No other significant associations were found between mean attitude change and attitudes towards the work environment and motivation for training.
8 DISCUSSION

The aim of the “Exploring Values” workshop was to increase staff awareness and influence their attitudes towards people with learning disabilities. The training was not intended to influence attitudes towards Normalisation, but to moderate extreme positive and negative attitudes towards more “middling” views.

8.1 SUPPORT FOR HYPOTHESES

8.1.1 Hypotheses 1 and 2

Findings suggest that the “Exploring Values” workshop was successful in moderating staff attitudes. In particular, staff who exhibited very positive/normalising attitudes prior to workshop attendance, exhibited significant change towards more realistic and less extreme attitudes, immediately after the workshop and at 3 months follow up. Because only 5 participants scored below the midpoint on the attitudes scale (indicating negative attitudes), it is difficult to generalise that the workshop had the effect of moderating attitudes of staff showing extremely negative/devaluing attitudes. Data trends however, indicated that the workshop did have some immediate but not long term moderating effects on staff who held the least positive attitudes towards people with a learning disability, prior to workshop attendance.

There are a number of possible reasons for these changes. Participants may have become clearer as to the nature and objectives of the workshop, and changed their responses to conform with the perceived view of the workshop leader, particularly as the questionnaires were not anonymous. However, it is unlikely that participants were able to remember their “conforming” responses from post workshop to 3 months follow up, which is when the largest change in attitudes took place. Therefore, it is likely that a genuine change in attitudes did occur as a result of the workshop. This
would support other research findings, (e.g.: Riding, 1997) indicating the usefulness of staff training in changing attitudes.

8.1.2 Hypotheses 3 and 4

Although not reaching acceptable levels of significance, data trends indicated that unqualified staff, and staff who did not view their jobs as assisting therapeutic programmes, appeared to benefit the most from training, compared to other staff groups. Staff who viewed their job role as incorporating more than just physical nursing, generally had more positive pre-workshop attitudes and were more likely to be qualified nurses and home managers. Qualified staff, who are likely to have had more contact with people with learning disabilities and experienced a greater amount of training in health and social care philosophies, appeared to benefit less from training, compared to unqualified staff who lack training and experience with this client group.

No other staff attitudes towards the work environment and motivation for training were associated with attitude change subsequent to training. This result appears to refute the theoretical assumptions made by Landseman-Dwyer and Knowles (1987), that contextual factors and staff characteristics can influence the effects of staff training. However, the effects of contextual and demographic variables on attitude change are unlikely to have been efficiently detected in this study because of the lack of variability in either a) the attitudes exhibited towards people with a learning disability or b) the attitudes exhibited towards the work environment and motivation for training, which were both highly positive and favourable. This may have been a genuine display of real and honest attitudes, however because of the lack of anonymity in this study, participants may have responded to the questionnaire in ways which placed them in a favourable light despite clear reassurance of confidentiality.
8.2 ADDITIONAL FINDINGS

8.2.1 Level Of Contact And Attitudes Towards People With A Learning Disability
It was found that staff who had worked longer in the field of learning disabilities, generally shown more positive, valuing attitudes prior to workshop attendance. This appears to lend support to previous research findings (Slevin, 1995; Slevin and Sines, 1996), that staff with higher levels of contact and longer duration’s of contact with learning disabled populations, are more positive in their attitudes compared to those with lesser contact.

8.2.2 Staff Grouping And Attitudes Towards People With A Learning Disability
A significant difference in mean attitude scores were found between different professional staff groups, with Home Managers and Qualified Nurses exhibiting significantly more positive attitudes towards people with learning disabilities, than unqualified care workers, prior to workshop attendance.

There are a number of possible reason for this finding. Qualified staff were found to have worked significantly more years with learning disabled people, compared to unqualified staff (T-tests: p< 0.001: See Appendix VI), therefore the difference in staff attitudes might have related to staff levels and duration of contact with this particular population. Alternatively, levels of staff education have been shown to affect attitudes towards people with a learning disability. Nurses educated to a higher standard (i.e.: qualified) have been found to hold more positive attitudes (e.g.: Slevin and Sines; 1996). Slevin (1995) suggests that education increases self awareness and cultivates a more sensitive and deeper understanding of disabled people.

9 METHODOLOGICAL CRITIQUE OF THE STUDY

9.1 RESEARCH WEAKNESSES
This study suffers from a number of methodological limitations, which question the reliability and validity of the results and conclusions.
9.1.1 Lack of Control Group

The major threat to the internal validity of this study was the lack of a control group. Within subject designs and quasi experimental designs are susceptible to a number of confounds, which are often avoided with the use of a control group. In the current study, the lack of a control group made it difficult to establish whether changes in staff attitudes were a direct result of attending the workshop, or due to some other confounding variable.

9.1.2 Demand Characteristics

In pre-post test designs, participants are able to determine to some extent, what changes are expected of him or her after intervention. Typically in this situation, the participant will try to co-operate, and this is commonly known as a demand characteristic. This demand characteristic is likely to have been present in the current study. Participants were required to exhibit attitudes towards a population, to which they would be expected to have positive views. They were also asked to supply their names on their attitude questionnaires, making it more difficult to be completely honest in their responses. In light of these problems, staff attitudes towards people with a learning disability prior to workshop attendance, and attitude changes after workshop attendance, may not have been a true representation of staff views.

9.1.3 Regression towards the mean

Examining the degree of attitude change for participants with extreme positive or negative scores, is vulnerable to the effects of “regression towards the mean”. Regression towards the mean is the likelihood that extreme scores on a dependent variable such as attitude scores will move towards the mean upon retesting, regardless of any intervention. This phenomenon can be accounted for by choosing a control group whose initial scores are equally extreme and are not subjected to the intervention before retesting. Staff with extreme positive views were found to be significantly less positive after workshop attendance. Without the use of a control
group, it is not possible to conclude that the change in attitude scores were a result of
the effects of the workshop or merely a regression of scores towards the mean.

9.1.4 Testing Effects

In within-subject designs, the fact that participants have been tested before, is likely to
effect the results of the next test, due to practice effects, familiarity with test material
etc. Using alternative forms of outcome measures or using a carefully chosen control
group, can account for testing effects so that study's results can be more accurately
interpreted. The current study had no control group to account for testing effects and
did not use alternative forms of the outcome measure. However, an attempt to control
for testing effects was made by reordering the attitude items on the post-workshop
questionnaire.

9.1.5 Problems with the Outcome Measure

The attitude scale designed specifically for this study, showed adequate inter item
reliability and face validity, however, it did not produce variable attitude scores at any
point of data collection, either as a complete scale or on individual items. This may
have been a result of poor questionnaire construction or a result of the demand
characteristics as mentioned previously. No other types of reliability or validity were
established for the questionnaire. On hindsight, use of an established questionnaire
such the ATDP might have been more appropriate.

9.2 RESEARCH STRENGTHS

This is one of only a few studies investigating this area of research. It is a whole
population survey, involving a high proportion of staff and a good response rate. It
attempts to address many of the research questions leading from Ridings study
(Riding, 1997) and is one of a few studies to include two post intervention measures.
Because of the methodological weaknesses detailed above, a more stringent level of
statistical significance was used (0.001) and results obtained were consistent with
previous studies, ie: qualified staff having more positive attitudes than unqualified staff.
The study is an extension of previous research because it attempts to look at more than just increasing positive attitudes towards people with a learning disability.

9.3 RECOMMENDATIONS FOR FUTURE RESEARCH

Due to the methodological flaws of this study, it was not possible to be conclusive as to the effects of the "Exploring Values" workshop on staff attitudes towards those with a learning disability. Future research needs to rectify the design problems in this study, in particular by incorporating a control group and standardised outcome measures. In addition, it was not possible from this study to conclude which part or parts of the workshop had the greatest effect on changing staff attitudes. The "Lifestyles for People with Mental Handicaps" pack (East Sussex Consultancy and Training Agency, 1985) was regarded as the major contributor to effecting staff attitudes, however, this was incorporated into a workshop which addressed a number of topics over a two day duration. One way of fully establishing the effects of the Lifestyles Package, would have been to compare attitude change between workshop participants and a control group of staff who completed the Lifestyles Package only.

10 CONCLUSION

Findings from this study suggest that training was somewhat successful in changing staff attitudes towards people with learning disabilities, and that changes in attitudes were sustained over a period of time. There was evidence that the workshop helped to moderate extreme positive attitudes and had a slightly greater impact on changing the attitudes of unqualified care staff towards people with a learning disability. However, the methodological limitations of the study, question the reliability of the data and limit the conclusions drawn. Further research is needed to improve on the methodological design, explore what sort of training has the greatest effect on changing staff attitudes, and whether changes in attitudes have a subsequent effect on staff behaviour towards people with a learning disability.
11 REFERENCES


APPENDIX I

Aims and Objectives of the “Exploring Values” Workshop.
EXPLORING VALUES IN WORKING WITH PEOPLE WITH LEARNING DISABILITIES.

A two day workshop for staff of St. Ebbas Epsom.

Date:

Venue:

Workshop Leaders: Brian Kay
Astrid Henderson
PROGRAMME

Day one

9.15  Introduction
      Identifying Objectives
      Setting the Scene


10.30 Coffee


12.00 Health Care Issues

12.30 Lunch

1.30  Lifestyle Mapping Exercise

2.45  Tea

3.00  Valuing People

4.30  Finish
PROGRAMME

Day two

9.15 Clarifying Objectives

9.30 Working in a Team

10.30 Coffee

10.45 Exploring Issues surrounding Managing Care
In-tray exercise

12.30 Lunch

1.30 Therapeutic Interventions with People
with Learning Disabilities

2.45 Tea

3.00 Building the Service

3.30 Action Plan/Pledges
Evaluation

4.30 Finish
EXPLORING VALUES IN WORKING WITH PEOPLE WITH LEARNING DISABILITIES.

Aims:-

To offer workshop participants the opportunity to explore the current philosophies of care and value systems underpinning the provision of services to people with learning disabilities in the current social and political climate and to explore their own beliefs and views in relation to caring for people with learning disabilities.

Objectives:-

That through participation in the workshop individuals will be able to:-

1. Describe current trends and developments in policy and philosophies underpinning provision of services to people with learning disabilities.

2. Explore personal values systems and relate them to their role within their work situation.

3. Identify key components of the Health of the Nation Strategy for People with Learning Disabilities and suggest ways in which recognition of the importance of physical health care is incorporated into service provision for people with learning disabilities.

4. Compare and contrast the experiences of people with learning disabilities being supported in community based services with those in more institutional based settings.

5. Examine ways in which people may feel valued and empowered and apply this to their work situation.
6. Discuss the benefits and advantages of utilising a team approach in working with people with learning disabilities.

7. Consider and evaluate a range of therapeutic approaches to the care of people with learning disabilities.

8. Define their contribution to meeting the needs of people with learning disabilities through their role within St Ebbas, Epsom.

9. Produce and action plan or pledge to apply information gained from the workshop to their work.
APPENDIX II

Pre, post and follow up questionnaires
<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Disagree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am very happy with the physical condition of my work place</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td>I feel that the work I do has little impact on improving the lives of the residents</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td>It is best for people with LD to only have non-disabled friends</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td>Staff team work is not essential for giving residents good care</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td>All residents should have access to public recreation facilities</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td>Residents should be involved in all decisions regarding their care</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td>It is a vital part of my job to assist with residents therapy programmes</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td>There are many tasks in my job that I do not enjoy doing</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td>It is essential for staff to always provide residents with privacy</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td>Attending this workshop is not a valuable use of my time</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td>I enjoy working with the residents on my home</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td>It is our duty to accommodate our residents every wish</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td>I am not happy with the shifts I work</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td>Little can be done to help severely handicapped residents to improve</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td>I work in an efficient staff team</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td>My job is to contain residents challenging behaviour, not to change it</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td>It is beneficial for people with LD to have separate facilities from the general population</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td>This workshop will not tell me anything new</td>
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</tr>
<tr>
<td>All people with LD can be taught to be independent</td>
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<td></td>
</tr>
<tr>
<td>Residents should not be given choice about where they live</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td>People with LD do not have the same emotions as non disabled people</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td>There is little opportunity for me to develop my career</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td>Residents are better off only making friends with other residents</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td>Punishment is sometimes the only way of controlling the behaviour of people with LD</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td>My individual approach to residents can make an important contribution in their care</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td>This workshop will change the way I view people with LD</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
</tbody>
</table>

THANK YOU FOR YOUR TIME
**POST WORKSHOP QUESTIONNAIRE**

*Please circle the number which most accurately reflects your own beliefs*

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Strongly Agree</th>
</tr>
</thead>
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<tr>
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<td>There are many tasks in my job that I do not enjoy doing</td>
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<td>Attending this workshop has not been a valuable use of my time</td>
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**THANK YOU FOR YOUR TIME**
**FOLLOW UP QUESTIONNAIRE**

Name: ........................................................................................................

*Please circle the number which most accurately reflects your own beliefs*

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</tr>
<tr>
<td>Punishment is sometimes the only way of controlling the behaviour of people with LD</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td>My individual approach to residents can make an important contribution in their care</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td>This workshop will change the way I view people with LD</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
</tbody>
</table>

THANK YOU FOR YOUR TIME
APPENDIX III

Information Sheet
The following questionnaire is part of a project looking at the effect of attending this workshop. It is being carried out by the psychology department at St. Ebba's for Frank Murphy. There will be a similar short questionnaire to fill out at the end of your workshop, and we will also be asking you to fill one out three months after the workshop.

All your answers will be treated in the strictest confidence and no individual data will be used. We only need your name so that we can keep all three questionnaires together - once they are collected you will be referred to as a number. We will not be referring any individual information back to your homes and your responses will not affect your job in any way.

Many of the questions are in the form of statements about which you are asked to rate your feelings. Please circle one number which corresponds most closely with your own beliefs (1 strongly disagrees with the statement and 6 strongly agrees with it). There are no right or wrong answers, only your feelings and thoughts. If there are any questions you do not wish to answer then please leave them blank.

We appreciate your time and effort in filling out these questionnaires and would like to thank you in advance for your help. Please do not hesitate to ask if you wish for more information concerning the project. We can be contacted on:

Zillah Webb (Clinical Psychologist) Extn: 3163
Victoria Hill (Clinical Psychologist in Training) Extn: 3165
Helena Stone Pearn (Assistant Psychologist) Extn: 3165

PLEASE COMPLETE:

| Name: ............................................. | Gender: M............... F............. |
| Age: ............................................. | Job title: ............................................. |
| Which home do you work on: ............................................. |
| Length of time worked with people with learning disabilities (LD): ............................................. |
| Length of time worked in St. Ebba’s: ............................................. |
| Have you ever worked with people with LD in the community?: ............................................. |
| Do you have any relatives with a learning disability?: ............................................. |
APPENDIX IV

Results from Mann-Whitney U tests, Spearman correlation's and a Kruskal Wallis One Way ANOVA to compare attitude change in relation to staff characteristics.
Table 1: Mann Whitney U Test results performed on Mean attitude change scores pre-post workshop and staff characteristics.

<table>
<thead>
<tr>
<th>Staff Variable</th>
<th>N</th>
<th>Mean Rank</th>
<th>U statistic</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>197</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td></td>
<td>95.90</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td></td>
<td>101.50</td>
<td>4523.0</td>
<td>0.4902</td>
</tr>
<tr>
<td>Has participant ever worked in the community</td>
<td>189</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td></td>
<td>87.13</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td></td>
<td>97.61</td>
<td>2967.0</td>
<td>0.2523</td>
</tr>
<tr>
<td>Does the participant have a relative with a learning disability</td>
<td>188</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td></td>
<td>84.08</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td></td>
<td>95.67</td>
<td>1407.5</td>
<td>0.3759</td>
</tr>
</tbody>
</table>

Table 2: Mann Whitney U Test results performed on Mean attitude change scores post workshop to 3 months follow up and staff characteristics.

<table>
<thead>
<tr>
<th>Staff Variable</th>
<th>N</th>
<th>Mean Rank</th>
<th>U statistic</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>176</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td></td>
<td>81.43</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td></td>
<td>93.87</td>
<td>3263.0</td>
<td>0.1075</td>
</tr>
<tr>
<td>Has participant ever worked in the community</td>
<td>170</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td></td>
<td>88.34</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td></td>
<td>84.54</td>
<td>2608.5</td>
<td>0.6607</td>
</tr>
<tr>
<td>Does the participant have a relative with a learning disability</td>
<td>169</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td></td>
<td>80.36</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td></td>
<td>85.55</td>
<td>1275.5</td>
<td>0.6693</td>
</tr>
</tbody>
</table>
Table 3: Kruskal Wallis Test results performed on mean attitude change scores pre-post workshop and staff job types.

<table>
<thead>
<tr>
<th>Job Titles</th>
<th>N</th>
<th>Chi-Squared</th>
<th>df</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unqualified Care workers</td>
<td>98</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Qualified nurses</td>
<td>55</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychologists</td>
<td>9</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Instructors</td>
<td>16</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home Managers</td>
<td>18</td>
<td>12.2213</td>
<td>4</td>
<td>0.0158</td>
</tr>
</tbody>
</table>

Table 4: Kruskal Wallis Test results performed on mean attitude change scores post workshop to 3 months follow up and staff job types.

<table>
<thead>
<tr>
<th>Job Titles</th>
<th>N</th>
<th>Chi-Squared</th>
<th>df</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unqualified Care workers</td>
<td>85</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Qualified nurses</td>
<td>50</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychologists</td>
<td>8</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Instructors</td>
<td>16</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home Managers</td>
<td>17</td>
<td>2.6548</td>
<td>4</td>
<td>0.6171</td>
</tr>
</tbody>
</table>

196
Table 5: Spearman correlation's for i) mean attitude change scores pre to post workshop and ii) post workshop to 3 months follow up and staff characteristics.

<table>
<thead>
<tr>
<th>Staff Characteristic</th>
<th>mean attitude change scores pre to post workshop</th>
<th>mean attitude change scores post workshop to 3 months follow up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>Rs= 0.0902 (N=155) p=0.264</td>
<td>Rs=0.0417 (N=137) p=0.628</td>
</tr>
<tr>
<td>Number of years worked in PLD</td>
<td>Rs=0.0617 (N=186) p=0.402</td>
<td>Rs=0.0205 (N=167) p=0.792</td>
</tr>
<tr>
<td>Number of years worked at St Ebbas</td>
<td>Rs=0.0955 (N=188) p=0.192</td>
<td>Rs=-0.0392 (N=169) p=0.613</td>
</tr>
</tbody>
</table>
APPENDIX V

Spearman correlation's performed between scores of mean attitude change and measures of pre-workshop staff attitudes towards their work environment and motivation for training.
<table>
<thead>
<tr>
<th>Questionnaire Items corresponding to staff attitudes towards the work environment and motivation for training.</th>
<th>Mean attitude change scores pre to post workshop</th>
<th>Mean attitude change scores post workshop to 3 months follow up</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am very happy with the physical condition of my workplace</td>
<td>Rs=-.0077 N=195 P=.914</td>
<td>Rs=.0796 N=174 P=.297</td>
</tr>
<tr>
<td>I feel that the work I do has little impact on improving the lives of the residents</td>
<td>Rs=-.1398 N=195 P=.051</td>
<td>Rs=.0381 N=175 P=.617</td>
</tr>
<tr>
<td>Staff team work is not essential for giving residents good care</td>
<td>Rs=-.0943 N=194 P=.191</td>
<td>Rs=-.1204 N=173 P=1.15</td>
</tr>
<tr>
<td>It is a vital part of my job to assist with residents therapy programmes</td>
<td>Rs=-.1994 N=194 P=.005</td>
<td>Rs=-.0401 N=173 P=.601</td>
</tr>
<tr>
<td>There are many tasks in my job that I do not enjoy doing</td>
<td>Rs=-.0463 N=192 P=.524</td>
<td>Rs=.0937 N=171 P=.223</td>
</tr>
<tr>
<td>Attending this workshop is not a valuable use of my time</td>
<td>Rs=-.1711 N=188 P=.019</td>
<td>Rs=-.0922 N=167 P=.236</td>
</tr>
<tr>
<td>I enjoy working with the residents on my home</td>
<td>Rs=-.0313 N=194 P=.665</td>
<td>Rs=.0845 N=173 P=.269</td>
</tr>
<tr>
<td>I am not happy with the shifts I work</td>
<td>Rs=-.1419 N=192 P=.050</td>
<td>Rs=.0642 N=172 P=.403</td>
</tr>
<tr>
<td>I work in an efficient staff team</td>
<td>Rs=-.004 N=195 P=.951</td>
<td>Rs=.0258 N=174 P=.736</td>
</tr>
<tr>
<td>My job is to contain residents challenging behaviour no to change it</td>
<td>Rs=.0201 N=186 P=.785</td>
<td>Rs= -.1057 N=166 P=.175</td>
</tr>
<tr>
<td>This workshop will not tell me anything new</td>
<td>Rs=-.0678 N=183 P=.362</td>
<td>Rs= -.1149 N=162 P=.146</td>
</tr>
<tr>
<td>There is little opportunity for me to develop my career</td>
<td>Rs=-.1433 N=195 P=.046</td>
<td>Rs= -.1423 N=174 P=.061</td>
</tr>
<tr>
<td>My individual approach to residents can make an important contribution to their care</td>
<td>Rs=-.0253 N=193 P=.727</td>
<td>Rs=.0436 N=173 P=.569</td>
</tr>
<tr>
<td>This workshop will change the way I view people with LD</td>
<td>Rs=.0923 N=183 P=.211</td>
<td>Rs= -.0364 N=164 P=.644</td>
</tr>
</tbody>
</table>
LARGE SCALE RESEARCH PROJECT

Eating Patterns in a Population of People with Learning Disabilities: Types, Prevalence and Associated Population Characteristics

July 1999

Year 3
1 ABSTRACT

AIM: To measure the type and prevalence of eating patterns in a population of people with learning disabilities. OBJECTIVE: To develop a valid and reliable instrument, in order to investigate relationships between eating patterns and other population variables. METHODS: 284 people with learning disabilities (aged 21 to 95) residing in a large institution, were surveyed using a questionnaire designed to measure different types and severity of eating patterns and population characteristics. RESULTS: A reliable and valid questionnaire, the PEQ, was developed. Four major dimensions of eating patterns emerged in the population under study using the PEQ. These were; reluctance to eat, preoccupation with food, concern for body image and difficulties with eating. Pica was also measured using individual questionnaire items. A mean of 30% of residents exhibited a reluctance to eat and 15% exhibited preoccupation with food. 9% of residents had some difficulties with chewing and swallowing and 10% exhibited non-food pica, at least some of the time. 7% of residents exhibited some concerns about body image. Eating patterns were associated with a number of population characteristics including gender, age, mental and physical health problems, medication, behavioural problems and levels of cognitive and physical ability. CONCLUSIONS: A range of eating difficulties exist within this population with PLD, and are of sufficient frequency to warrant greater research and clinical attention. Adults with learning disabilities do exhibit concerns about body image and this appears to be most prevalent in those with higher levels of cognitive ability. Further in-depth assessment using semi-structured interviews, might help to identify those who have an eating disorder such as anorexia or bulimia nervosa. The links between eating difficulties and population characteristics helps to identify those at greater risk of developing eating problems. Further research is necessary to a) establish reliable and valid diagnostic criteria and measuring tools for eating patterns in this population, b) establish the etiological nature of these patterns and c) develop treatment and prevention strategies for these eating disturbances.
2 INTRODUCTION

A number of different eating problems have been identified in people with learning disabilities (PLD). These include problems with regurgitation and rumination, swallowing problems, lack of appetite, ravenous and perverted appetite (pica) (Kanner, 1937, Danford and Huber, 1981). There have also been case studies in the literature, reporting the occurrence of eating disorders such as anorexia nervosa. These eating dysfunctions have led to serious clinical problems such as growth retardation, weight loss, malnutrition, obesity, and surgery.

Only a few studies have reported the prevalence of eating difficulties in PLD. Many of these have concentrated on paediatric populations rather than adult populations and focussed more on pica than on any of the other eating difficulties. Only one study to date has systematically investigated the prevalence of eating difficulties in an adult population with learning disabilities and reported that 42% of the population had some form of eating dysfunction (Danford and Huber, 1981). No study to date however, has attempted to investigate the prevalence of anorexia and bulimia nervosa in a large scale population survey.

The following sections in this introduction will focus on the prevalence and etiological factors for eating patterns found in PLD and other populations. A critique of previous prevalence studies will be presented, followed by a rationale for the current study.

2.1 PICA

The term Pica originated from the Latin word for Magpie. Magpies are birds that are renowned for stealing objects. Bicknell (1975) defined pica as

"the desire to ingest or the ingestion of substances usually considered inedible, continuing beyond the normal developmental phase of occasional indiscriminate and experimental mouthing and swallowing"
The International Classification of Diseases – version ten (ICD-10), describes Pica as

"persistent eating of non nutritive substances occurring as one of many symptoms that are part of a more widespread psychiatric disorder or occurring as a relatively isolated psychopathological behaviour (W.H.O, 1992)"

Objects that are ingested by those who suffer from pica may include carpet fluff, cigarettes, faeces or on occasion larger objects like belts. The ingestion of inappropriate foods may include frozen or uncooked foods.

2.1.1 Prevalence of Pica

Pica is a problem which is often exhibited by infants, young children and pregnant women (Walker et al, 1997) and is also found in PLD. A number of surveys utilising staff reports and direct observation, have studied the prevalence of Pica in institutionalised populations of people with learning disabilities. In the first of these surveys Danford and Huber (1981), found that 26% of 991 institutionalised people with learning disabilities (aged 11 – 88) suffered from Pica (5.4% food pica; 16.7% non food pica; 3.7% food and non-food combined). McAlpine and Singh (1986) surveyed 607 institutionalised residents (aged 15-73) and found that only 9.2% engaged in Pica, a much lower figure than found by Danford and Huber despite the employment of similar survey techniques. In a more recent study, Tewari et al (1995) surveyed 246 hospitalised adults with learning disabilities (aged 24 – 79) and found that 10% had Pica. Of those, 52% had Pica for cigarette butts and 24% had pica for faeces. In addition to general rates of Pica, there is evidence from all these studies that Pica occurs more often in those with a severe rather than mild learning disability (Danford and Huber, 1981; McAlpine and Singh, 1986) and decreases with age (Danford and Huber, 1981; McAlpine and Singh, 1986; Tewari et al, 1995). Pica has also been found to occur more often in those suffering from autism (Kinnell 1985). Currently there is a lack of prevalence studies of Pica for PLD populations living in the community.
2.1.2 Etiology of Pica

The etiology of Pica is still not fully understood despite numerous investigative studies.

Bicknell (1975) suggested that Pica was a symptom of developmental lag of oral behaviour, considered normal in children under the age of 18 months. This could account for the high prevalence of Pica found in children and adults with learning disabilities, particularly those with severe learning disabilities. This cannot however explain the high prevalence of Pica in pregnant women, and children with no disabilities.

Many incidences of Pica in pregnancy and children have been linked to nutritional deficiencies, particular deficiencies in iron (e.g.: Crosby, 1976, Arbiter and Black, 1991, Moore and Sears, 1994) and zinc (Halstead, 1977; Walker et al, 1997). Treatment with iron and zinc supplements has often led to a decrease or cessation of Pica. However, Pica has also been found to inhibit the absorption of iron through the ingestion of certain substances, resulting in anaemia that is secondary to Pica. It has also been shown that iron deficiency is coincidental rather than causal in the condition (Bicknell, 1975). The nature of the association between Pica and iron deficiency should therefore be interpreted with caution.

A number of studies have proposed that Pica is a symptom of psychopathology. Jawed et al (1993), reported a case of a person with severe learning disabilities, whose Pica worsened during episodes of depressive illness and reduced when treated with antidepressant medication. This suggests that depression exacerbates Pica. It does not however, prove it to be a causal factor. Stein et al (1996) found a link between Pica and Obsessive-Compulsive Disorder, which was successfully treated with a serotonin re-uptake inhibitor, suggesting a link between Pica, psychopathology and neurochemical actions in the brain. Kinnell (1985) carried out an empirical study to investigate the association between autism and Pica. He found that Pica was exhibited not only more often by subjects with autism, but also by three subjects in the control group who also happened to have a psychotic disorder. Kinnell went on to speculate that Pica was a symptom of psychotic tendencies rather than a symptom of...
poor communication, as speculated in previous literature (Comments, 1975). Kinnell concluded that more research was needed to help establish the causal nature of the association between Pica and psychiatric illness.

Pica has been thought to represent a means of dietary restraint for controlling or losing weight, thus suggesting it to be a symptom of an eating disorder such as anorexia or bulimia nervosa. Indeed, McLoughlin and Hassanyeh (1990) reported a case of a 51 year old woman with pica and anorexia nervosa, who had an intense fear of becoming fat. Her diet was restricted and bizarre. She ate up to 40 ice cubes a day and also consumed frozen soft fruit. However, she was also found to suffer from iron deficiency anaemia, so it was difficult for the authors to conclude that Pica was primarily a strategy for weight control. There is a lack of other research studies linking Pica and Eating Disorders.

Singhi and Singhi (1981) investigated the link between psychosocial stress and Pica. In their study, they found that 50 children with iron deficiency anaemia and Pica, had greater psychosocial stress (maternal deprivation, parental separation, neglect, abuse, attachment problems) compared to 50 children with iron deficiency anaemia and no Pica. Psychosocial stress was therefore concluded to be a significant predisposing factor for Pica, in addition to mineral deficiencies.

2.2 RUMINATION AND SWALLOWING PROBLEMS AND APPETITE DISTURBANCES

2.2.1 Prevalence in PLD

There are very few studies to date which have investigated the frequency of other eating dysfunctions in PLD such as rumination (regurgitation and self vomiting), hyperphagia (excessive appetite for food), aerophagia (air swallowing) and anorexia (lack of appetite for food).

The prevalence of rumination in children with learning disabilities has been estimated at between 10-15% (Cadman et al, 1978; Sondheimer and Morris, 1979) and Danford
and Huber (1981) found that 5.5% of their adult population with learning disabilities exhibited rumination. They found that significantly more males with learning disabilities exhibited rumination compared to females and that rumination decreased with age and was more prevalent in those with a severe or profound learning disability. Rumination was also associated with food supplements, iron and antacids and correlated highly with being grossly underweight.

Danford and Huber (1981) found that 2.7% of their institutionalised population exhibited aerophagia (air swallowing), that decreased with age and was associated with iron supplements and being grossly underweight. 13.7% of the population sample exhibited hyperphagia (excessive appetite). This was associated with psychotropic medication and vitamins, behavioural problems and being obese. 7.2% exhibited anorexia (defined as lack of appetite), which decreased with age and was associated with medical problems, medication and being underweight. Danford and Huber (1981) concluded that eating dysfunctions were prevalent in this population and thus warranted further etiological investigations.

### 2.2.2 Prevalence in Other Populations

Similar eating dysfunctions to those found in PLD have also been reported in adults with dementia and in children with no disabilities. Morris et al. (1989) investigated the eating habits of people suffering from dementia, using information from relatives who were able to act as informants for the whole period of the dementia. They found that changes in eating habits were common and included increases (26%) and decreases (63%) in appetite, altered food choice (37%), Pica (15%) and difficulties with feeding (60%). There were no significant associations between eating patterns and functional or physical illness, however the number of subjects in the study was very small (N=33).

The incidence of feeding problems in children range from 25% to 35% overall (Linscheid, 1992), with estimates as high as 45% for normally developing children. These feeding problems have been linked to physical disabilities (e.g.: gastroesophageal reflux, cystic fibrosis and cancers) and to the psychosocial development of the child. During the toddler period, children begin to assert
themselves as a way of expressing autonomy (Erikson, 1950). Food refusal and fussiness is one way of obtaining some autonomy in a socially acceptable way. Eating and feeding problems can therefore been seen as a normal and important process of development (Kuczynski et al, 1987), depending on the severity of the problems and degree of associated weight loss.

2.2.3 Etiology of Rumination and Swallowing Difficulties

Feeding problems such as rumination and aerophagia have been linked to dysphagia (swallowing problems), often relating to problems with oesophageal muscle control and resulting in under-nutrition and weight loss. Kennedy et al (1991) carried out a large scale survey on hospitalised and community based adults and children with learning disabilities. They found that over 60% of their sample were underweight as a result of swallowing difficulties. Rumination has also been associated with cerebral dysfunction (brain damage) and digestive problems (Biox-ochoa, 1979).

2.2.4 Etiology of Appetite Disturbances

Hyperphagia and anorexia (disturbances in appetite) have been linked to a number of possible etiological factors.

Chemicals and structures in the brain (e.g.: serotonin, noradrenaline, hypothalamus, medial temporal lobe) are all known to be involved in controlling food intake and food choice. Damage to these mechanisms, particularly to the hypothalamus has resulted in disruption of appetite (Groover, 1978).

Physical illness can also cause a loss of appetite. (Pereira and Bergum (1987) found that when normal children suffered with upper respiratory infections, diarrhoeas and fevers, food intake was reduced by 15-20%. Measles resulted in prolonged and profound depression of appetite, and caused weight loss in the affected children.

Certain antidepressant and neuroleptic medications have also been associated with changes in appetite. Tricyclics (TCAs) and some monoamine inhibitors (MAOIs) can produce carbohydrate craving, increased appetite and weight gain (e.g.: Harris et al, 1986; Berken et al, 1984). Stein et al (1985) found that 38% of their subjects taking
tricyclic medication, reported excessive appetite, and 34% had a craving for sweets. Yeragani et al, (1988) investigated the incidence of carbohydrate craving associated with a number of different antidepressant drugs and found that 10% of subjects developed cravings, with the highest incidence occurring in subjects taking amitryptiline. Other antidepressant drugs such as fluvoxamine (MAOI) and fluoxetine (SSRI) have been found act as appetite suppressants (Fernstrom, 1989; Silverstone, 1992).

Neuroleptic medication such as chlorpromazine, thioridazine and clozapine have all been associated with weight gain whereas molindone and pimozide has been associated with weight loss (Stanton, 1995). Neurological and metabolic mechanisms are thought to be responsible for the effects of medication on appetite and weight, however the underlying causes are is still poorly understood.

There is also research showing an association between psychiatric illness such as depression, appetite and weight changes. Diminished appetite and weight are regarded as prominent symptoms of depressive illness (e.g.: Kazes et al, 1993). A tendency for some people with depression to gain weight has also been recognised. According to Hopkinson, 1981, about 85% of depression sufferers lose weight and 15% gain weight. These changes in weight are thought to relate to changes in the levels of serotonin and norepinephrine in the brain.

Appetite disturbances are associated with certain genetically determined disorders, and mental retardation. Those with disorders such as Prader-Willi syndrome, Bardet-Biedl syndrome, Cohen syndrome and Borjeson-Forssman-Lehmann syndrome, often exhibit excessive appetite and/or obesity (Sarimski, 1996, Gunay et al, 1997). Hypothalamic–pituitary abnormalities are thought to be the cause of these eating and weight problems, however knowledge is still insufficient with regards to the underlying pathophysiological mechanisms. Children with Williams-Beuren syndrome have been shown to have selective food refusal (Sarimski, 1996) and this is thought to be a result of feeding and gastrointestinal problems (Pankau et al, 1994).
2.3 EATING DISORDERS – ANOREXIA AND BULIMIA NERVOSA

The prevalence of eating disorders has been studied for the general population and high risk groups such as adolescent and adult females and those with psychiatric illness. Some studies are beginning to recognise the need for measuring the occurrence of eating disorders in pre-pubertal children. Very little research has been carried out to investigate the occurrence and risk factors for eating disorders in populations with PLD. One of the aims of the current study was to develop a broad assessment instrument, which might detect some symptoms of eating disorders in this population and form the basis for future research in this area.

2.3.1 Characteristics of Anorexia and Bulimia Nervosa

Anorexia Nervosa is a psychiatric disorder, characterised by a) an intense fear of gaining weight, b) a disturbance of body image and c) refusal to maintain body weight above a minimally normal weight for age and height. Sufferers of anorexia believe that they are fat and often have an obsessive desire to be thinner. They will use a number of methods to lose weight including inappropriate fasting, use of laxatives, diuretics and exercise. Weight loss does not shift their delusion of being overweight.

Bulimia Nervosa is characterised by a) recurrent episodes of binge eating b) compensatory behaviour to avoid weight gain (self induced vomiting, laxative use, fasting etc) and c) over-concern about body shape and weight (Diagnostic and Statistical Manual of Mental Disorders 4th edition (DSM-IV); American Psychiatric Association, 1994).

Anorexia and bulimia are not mutually exclusive disorders. Approximately 40% of those with anorexia have a bulimic phase within the course of their illness (Kreipe (1995). A separate diagnostic category exists for this type of presentation in DSM-IV, in which dieting and binge eating are intermixed.

Those who have an eating disorder but do not meet all the diagnostic criteria for bulimia, anorexia or a mixed disorder, are categorised as having “eating disorder not otherwise specified” (DSM-IV).
2.3.2 Prevalence of Eating Disorders in PLD

There is a lack of studies investigating the prevalence of eating disorders in PLD perhaps because they are thought to be rare in this population and also difficult to measure and diagnose. Thomas (1994) argues that anorexia nervosa is under-diagnosed in PLD, possibly because not all cases present with all diagnostic features as stated in DSM-IV or ICD-10. People with learning disabilities, particularly severe learning disabilities may not be able to express body image distortion or other features of anorexia due to communication difficulties. Anorexia has also been found to co-exist with depression in normal and PLD populations and both disorders share similar symptoms. Without all symptoms of anorexia being exhibited in PLD, making a differential diagnosis between anorexia and depression is very difficult. Refusal to eat may be interpreted as attention seeking behaviour and this may also pose a diagnostic problem. Refusal to eat and weight loss may result from other factors such as physical difficulties with eating and metabolic disorders leading to malnutrition.

A few single case studies of eating disorders in PLD are reported (Hurley and Sovner, 1979, Fox et al, 1981, Cottrell and Crisp, 1981, Mohl and McMahon, 1980; Szymanski and Biederman, 1984; Holt et al, 1988, Thomas, 1994). In their research paper, Mohl and McMahon (1980) reported a case of a 20 year old woman with borderline learning disabilities, anorexia nervosa and schizoaffective disorder. Her anorexic symptoms included amenorrhea, episodic binge eating, laxative abuse and marked weight loss. Szymanski and Biederman (1984) reported a case of a 33 year old woman with Downs syndrome and depression who also had a diagnosis of anorexia nervosa. She exhibited extreme weight loss, refusal to eat and loss of menarche. She did not believe that she was underweight and sought constant reassurance that she was not fat. Thomas (1994) reported a case of a 35 year old woman with severe learning disabilities and anorexia nervosa, with symptoms such as food avoidance, self induced vomiting, beliefs about being fat and marked weight loss.
2.3.3 Prevalence of Eating Disorders in the General Population

A number of studies have attempted to measure the prevalence rates of anorexia and bulimia nervosa in the general population. They have found that between 0.02% and 0.2% of the population suffer from anorexia (Hoek, 1991; Lucas, et al, 1991; Whitehouse et al, 1992; Rooney et al, 1995) and 1% of the population suffer with bulimia nervosa (King et al, 1989; Bushell et al, 1990). Eating disorders are not found uniformly in these population studies. 80-90% of sufferers are female (Hoek, 1991), more than 95% are Caucasian and over 75% are adolescents (Kreipe, 1995). Most sufferers have been found to belong to the middle to upper socio-economic classes (King, 1989).

A number of studies have measured eating behaviour and eating attitudes in pre-pubertal children. Maloney et al (1989), surveyed 318 girls and boys between the age of 8-13 years, using the children's version of the Eating Attitudes Test (ChEAT) and a dieting questionnaire. They found that 45% of children wanted to be thinner and 37% had already tried to lose weight and 6.9% scored in the anorexia range. Veron-Guidry and Williamson (1996) also used the ChEAT to survey the eating patterns of 257 children between the ages of 8 to 13 and found that 12.1% scored in the anorexia range, 40.5% wanted to be thinner, 13.5% were dieting and 1.3% wanted to vomit after eating. Other studies have measured body dissatisfaction in children as young as 11 years old (Salmons et al, 1988, Sherman et al, 1995).

2.3.4 Prevalence of Eating Disorders in High Risk Groups

Many more studies have concentrated on measuring eating disorders within the high-risk groups (i.e. adolescent females and young adults). In general, studies have found that between 0.2% and 0.8% of young females (aged between 11 and 35) suffer from anorexia and between 0.9% and 3% of females suffer from bulimia nervosa (Hoek, 1993, Whitehouse et al, 1992, Kendler et al, 1991, Fairburn and Beglin, 1990). Partial eating disorders have a higher prevalence rate of between 3-5% in women (Kendler et al, 1991; Button and Whitehouse, 1981).

Eating disorders have also been found to co-exist with other psychiatric disorders such as schizophrenia (Deckelman et al, 1997) and depression (Lee et al, 1985; Walsh...
et al, 1985). Hence a number of studies have also looked at the prevalence of anorexia and bulimia in psychiatric populations. These studies have shown higher prevalence of eating disorders in psychiatric patients compared to the general population, with gender differences remaining similar. For example, Johnson and Hillard (1990) interviewed 143 patients from an emergency psychiatric population and found that 3% of women and 2.6% of men suffered from bulimia nervosa. No cases of anorexia were found. Hay and Hall (1991), used an eating disorders screening questionnaire on 107 recently admitted psychiatric inpatients and found that 6.5% of women and 0.9% of men had bulimia nervosa and ten patients (6 women and 4 men) had eating disorders not otherwise specified.

A number of these prevalence studies, used screening questionnaires, such as the Eating Attitudes Test (EAT: Garner and Garfinkel, 1979) or semi-structured interviews, based on DSM diagnostic criteria, to help identify eating disorders within population samples. More recent studies used a two-stage approach (utilising both questionnaire screening and semi-structured interview) as it was considered a more sophisticated and robust methodological procedure for identifying eating disorders. The differences in screening tests or interview procedures, as well as sample differences between studies, is likely to have contributed to the diversity of prevalence rates for eating disorders.

2.3.5 Etiology of Eating Disorders

Kreipe (1995) offered a conceptualisation of the pathogenesis of eating disorders based upon predisposing, precipitating and maintaining factors. He stated that predisposing factors for eating disorders include 1) being female in a culture where thinness for women is highly valued (Russell, 1992), 2) having perfectionist ideations (Fosson et al, 1987), 3) having difficulty expressing emotions 4) having difficulty resolving conflict and 5) having low self esteem. Some of these difficulties (i.e. conflict avoidance, lack of self expression) have been linked to family dysfunction (e.g. Palazzoli, 1974). Additionally, evidence is growing that trauma particularly childhood sexual abuse, may contribute to the development of eating disorders in adolescence (Palmer et al, 1990). Also, genetic factors are thought to play a role in the etiology of anorexia nervosa (e.g. Holland et al, 1988). Precipitating factors revolve
around factors normally associated with adolescence, such as fears of maturity and sexual development, identity conflicts and struggles for autonomy (Crisp, 1980). Maintaining factors include biological and psychological reinforcers such as malnutrition (e.g. Wakling, 1985), weight loss, denial or sense of satisfaction and power (Kreipe, 1995).

2.4 CRITIQUE OF PREVALENCE STUDIES OF EATING DYSFUNCTIONS IN PLD.

No large scale studies have attempted to measure the prevalence of symptoms of eating disorders in a PLD population. Danford and Huber (1981) carried out an extensive large scale survey of eating problems in a institutionalised population with learning disabilities and looked at associations with population characteristics. They choose however, only to investigate the prevalence of a limited and predefined set of eating dysfunctions and failed to include measures of symptoms pertaining to bulimia and anorexia nervosa. O'Brien and Whitehouse (1990) carried out a study of deviant eating patterns in a community population with learning disabilities and examined their relationship to psychiatric illness. However, they also did not measure eating patterns, associated with anorexia and bulimia. They attempted to measure associations between deviant eating patterns and different types of psychiatric illness, but the number of subjects in their study was small (n=48) and even smaller within each diagnostic group (range 2-15 subjects). Therefore, relationships between eating patterns and psychiatric diagnosis might easily have been missed. O'Brien and Whitehouse did not report the actual prevalence of eating patterns for the whole sample population and did not attempt to look at associations between eating patterns.

2.5 RATIONALE FOR CURRENT STUDY

There is still a lack of research investigating the types and severity of eating problems occurring in PLD, and particularly there is a lack of research looking at the occurrence of eating disorders such as anorexia and bulimia nervosa. There is also a lack of knowledge of associated population characteristics that may help to identify those at greater risk from disordered patterns of eating. The current study aimed to a)
investigate whether clinically relevant eating problems did exist within this population and b) to identify characteristics that predict those who appear to be at greater risk. This would enable preventative measures or treatments for eating difficulties in this population.
3 AIMS, RESEARCH QUESTIONS AND HYPOTHESES

3.1 AIM, OBJECTIVES AND RESEARCH QUESTIONS

3.1.1 Aim
To measure the type and prevalence of eating patterns in a population of people with learning disabilities.

3.1.2 Objectives
To develop a reliable and valid instrument in order to investigate eating patterns in a PLD population and investigate relationships between eating patterns and other population characteristics.

3.1.3 Main Research Questions
1. What are the types of eating patterns exhibited by an institutionalised population with learning disabilities? Are they the same or similar to those identified in previous research studies?
2. What is the prevalence of these eating patterns? How does the prevalence compare to previously reported figures or prevalence within other populations?
3. Are certain eating patterns associated with other population variables such as; Age and gender; Weight status and dieting; Types of medication; Types of mental illness; Autism; Behavioural problems; Types of medical problems; Levels of learning disability; Levels of physical ability (Mobility, vision and hand-eye coordination).

3.2 HYPOTHESES

3.2.1 Hypotheses Based On Research On Eating Difficulties In PLD
Given the limited knowledge of eating difficulties and disorders within this population, this is essentially an exploratory study. However, knowledge from past research enables some specific hypotheses to be generated with regard to the types of
eating patterns that might be expected in this population and their association with population characteristics. These are as follows;

H1: There will be evidence of a range of different types of eating difficulties within a diverse population of people with learning disabilities. These eating difficulties will include pica, lack of appetite, ravenous appetite, regurgitation, and symptoms of dysphagia.

H2 There will be associations between pica and the following population characteristics;
   a) Autism
   b) Mental illness, specifically psychosis
   c) Level of learning disability
   d) Reports of anaemia
   e) Age

H3 There will be an association between levels of physical ability and eating difficulties.

3.2.2 Hypotheses Derived From Research On Eating Difficulties In The General Population

It is assumed that a population of people with learning disabilities will share characteristics with the general population in relation to dieting and eating behaviours. The following hypotheses are derived from past research in this area on normal child, adolescent and adult populations.

H4 There will be a difference between male and female members of the sample population, in the frequency of eating difficulties/behaviours that have in the general population been associated with anorexia and/or bulimia.

H5 There will be an association between the presence of mental health problems such as depression and eating difficulties.

H6 There will be an association between physical health problems and eating difficulties, particularly reduction in appetite.
4 METHODS

4.1 STUDY DESIGN

A self-administered questionnaire survey was used to obtain data on the type and frequency of eating patterns in a sample population of people with a learning disability. In addition, other population characteristics were also surveyed, (medical and physical health, behavioural problems, levels of ability, weight, diets and feeding behaviours) as they were hypothesised to relate to different types of eating patterns.

4.2 PARTICIPANTS AND SAMPLE POPULATION

4.2.1 Sample Population

A population of 338 residents (99% of total population) from a long stay institution for people with learning disabilities were surveyed over a two month period (May – July 1998) in order to ascertain their patterns of eating and other population characteristics. The population was of mixed gender and ranged in age from 21 to 95 years. They resided in 21 individually managed homes, located within the hospital grounds. Four homes were delegated to care for those residents with moderate to severe challenging behaviour, and 9 homes cared for those with both physical and learning disabilities.

4.2.2 Participants

Qualified nursing staff from each residential home in the hospital were required to fill out questionnaires on residents under their care.

4.3 MEASURES

The author designed a questionnaire (Appendix 1), to measure patterns of eating and other population characteristics. It was designed to be completed by care staff working with people with learning disabilities.
4.3.1 Section 1: Demographics, Mental and Physical Health

Twelve questionnaire items were designed to measure population demographics, and gather information on mental and physical health, medication and behavioural difficulties (Table 1/Appendix I).

4.3.2 Section 2: Levels Of Ability

Seven questionnaire items were designed to gather information on residents' cognitive and physical abilities. Each question was designed to obtain ordinal data (using scales of variable points), where a high score indicated high level of ability and a low score indicated a low level of ability (See Table 1 and Appendix I).

4.3.3 Section 3: Feeding, Diets and Weight

Seven questionnaire items were designed to gather information on a) residents' ability to feed themselves b) whether residents were on special diets and what type of diets c) whether they were overweight or underweight and d) whether residents had lost weight or gained weight in the last 3 months (See Table 1 and Appendix I).
TABLE 1  Population characteristics measured by the PEQ

<table>
<thead>
<tr>
<th>Section of Questionnaire</th>
<th>Variable</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Section 1: Demographics/Mental and Physical Health</strong></td>
<td>Gender</td>
</tr>
<tr>
<td></td>
<td>Age</td>
</tr>
<tr>
<td></td>
<td>Height and weight</td>
</tr>
<tr>
<td></td>
<td>Medication</td>
</tr>
<tr>
<td></td>
<td>Mental health problem</td>
</tr>
<tr>
<td></td>
<td>Developmental disorder</td>
</tr>
<tr>
<td></td>
<td>Behavioural problems</td>
</tr>
<tr>
<td></td>
<td>Medical problems</td>
</tr>
<tr>
<td></td>
<td>Illness over last 6 mnths</td>
</tr>
<tr>
<td></td>
<td>Condition of Teeth</td>
</tr>
<tr>
<td></td>
<td>Periods (female only)</td>
</tr>
<tr>
<td></td>
<td>Contraceptive Pill</td>
</tr>
<tr>
<td><strong>Section 2: Level of Abilities</strong></td>
<td>Expressive Language</td>
</tr>
<tr>
<td></td>
<td>Receptive Language</td>
</tr>
<tr>
<td></td>
<td>Level of Supervision</td>
</tr>
<tr>
<td></td>
<td>Mobility</td>
</tr>
<tr>
<td></td>
<td>Hand Control</td>
</tr>
<tr>
<td></td>
<td>Visual ability</td>
</tr>
<tr>
<td></td>
<td>Learning Disability</td>
</tr>
<tr>
<td><strong>Section 3: Feeding, diets, weight</strong></td>
<td>Feeding ability</td>
</tr>
<tr>
<td></td>
<td>Special Diet</td>
</tr>
<tr>
<td></td>
<td>Type of Diet</td>
</tr>
<tr>
<td></td>
<td>Weight status — Underweight/overweight</td>
</tr>
<tr>
<td></td>
<td>Weight loss/gain</td>
</tr>
</tbody>
</table>

4.3.4  **Section 4: Eating Patterns**

Questionnaire items were devised to measure a variety of eating patterns, previously found in learning disabled populations and/or in the normal population (child and adult). Questionnaire items were devised to measure the following eating patterns/behaviours: food refusal, food fads, pica (eating of non foods and inappropriate foods), rumination and vomiting, symptoms associated in the general population with anorexia and bulimia (disturbance/preoccupation with body image, food refusal, over-exercise, bingeing and self induced vomiting), excessive appetite and overeating, chewing and swallowing problems, regurgitation.
32 items (See Table 2 for list of questionnaire items) were devised to measure eating patterns in the sample population. Each item was worded in the form of a statement, and participants (nursing staff) were required to respond to each item using a 5 point likert scale. An extra category was provided, which allowed participants to indicate when an eating pattern was severe enough to require special restrictions or programme. A “non-applicable” category was also provided for residents who may not have been able to exhibit eating patterns because of physical immobility and/or communication difficulties.

4.4 PILOT STUDY AND CONSULTATIONS.

Prior to the main study, a smaller study was carried out in order to pilot the PEQ. Staff from a Community Team for People with Learning Disabilities, were asked to fill out a pilot version of the PEQ on clients for whom they were keyworkers. They were also asked to provide written comment on the questionnaire. 27 pilot questionnaires were completed and returned with comments. In addition to the pilot study, comments about the structure of the questionnaire were obtained from the following sources:

A clinical psychologist working in the long stay institution at which the main study took place; a dietician from the same institution; an assistant psychologist working in a community team for people with learning disabilities.

Comments from the pilot study and consultations, resulted in a number of vital changes to the questionnaire prior to the main study. A number of extra questions were added for measuring additional population characteristics (height, weight, illness in last 6 months, condition of teeth, hand control, vision). For questions relating to Eating Patterns, two items were added and 11 questions were reworded.
<table>
<thead>
<tr>
<th>Item No.</th>
<th>Questionnaire Items</th>
<th>Type of Eating Pattern that Item was Designed to Measure</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Avoids eating sweet and/or fatty foods</td>
<td>Dieting / Anorexia/Bulimia*</td>
</tr>
<tr>
<td>2</td>
<td>Chooses only to eat sweet and/or fatty foods</td>
<td>Faddy Eating</td>
</tr>
<tr>
<td>3</td>
<td>Eats a limited variety of food</td>
<td>Faddy Eating</td>
</tr>
<tr>
<td>4</td>
<td>Eats inappropriate (i.e.: frozen or uncooked) foods</td>
<td>Pica</td>
</tr>
<tr>
<td>5</td>
<td>Eats inedible (non-food) objects</td>
<td>Pica</td>
</tr>
<tr>
<td>6</td>
<td>Takes longer than others to eat a meal</td>
<td>Food Refusal/Anorexia/Bulimia*</td>
</tr>
<tr>
<td>7</td>
<td>Eats a meal more quickly than others</td>
<td>Excessive Appetite/Overeating</td>
</tr>
<tr>
<td>8</td>
<td>Refuses to eat his/her meal</td>
<td>Food Refusal/Anorexia/Bulimia*</td>
</tr>
<tr>
<td>9</td>
<td>Needs encouragement to eat and/or finish a meal</td>
<td>Food Refusal/Anorexia/Bulimia*</td>
</tr>
<tr>
<td>10</td>
<td>Doesn't finish his/her meal</td>
<td>Food Refusal/Anorexia/Bulimia*</td>
</tr>
<tr>
<td>11</td>
<td>Eats very little</td>
<td>Food Refusal/Anorexia/Bulimia*</td>
</tr>
<tr>
<td>12</td>
<td>Eats more food than others</td>
<td>Excessive Appetite/Overeating</td>
</tr>
<tr>
<td>13</td>
<td>Drinks to excess</td>
<td>Excessive Appetite/Overeating</td>
</tr>
<tr>
<td>14</td>
<td>Requests food between mealtimes</td>
<td>Excessive Appetite/Overeating</td>
</tr>
<tr>
<td>15</td>
<td>Chokes on food</td>
<td>Chewing and Swallowing</td>
</tr>
<tr>
<td>16</td>
<td>Lets food sit in his/her mouth</td>
<td>Chewing and Swallowing</td>
</tr>
<tr>
<td>17</td>
<td>Chews food for long periods of time</td>
<td>Chewing and Swallowing</td>
</tr>
<tr>
<td>18</td>
<td>Regurgitates their food</td>
<td>Regurgitation</td>
</tr>
<tr>
<td>19</td>
<td>Searches for food between meals</td>
<td>Excessive Appetite/Overeating</td>
</tr>
<tr>
<td>20</td>
<td>Hides food</td>
<td>Excessive Appetite or Anorexia/Bulimia*</td>
</tr>
<tr>
<td>21</td>
<td>Takes food</td>
<td>Excessive Appetite</td>
</tr>
<tr>
<td>22</td>
<td>Chooses only to eat certain coloured and/or textured foods</td>
<td>Faddy Eating</td>
</tr>
<tr>
<td>23</td>
<td>Complains of being hungry or indicates hunger</td>
<td>Excessive Appetite</td>
</tr>
<tr>
<td>24</td>
<td>Eats large amounts of food within a short period of time outside of mealtimes</td>
<td>Bingeing / Bulimia*</td>
</tr>
<tr>
<td>25</td>
<td>Appears anxious at mealtimes</td>
<td>Food Refusal/Anorexia/Bulimia*</td>
</tr>
<tr>
<td>26</td>
<td>Dislikes eating</td>
<td>Food Refusal/Anorexia/Bulimia*</td>
</tr>
<tr>
<td>27</td>
<td>Talks about his/her weight</td>
<td>Anorexia/Bulimia*</td>
</tr>
<tr>
<td>28</td>
<td>Thinks they are fat</td>
<td>Anorexia/Bulimia*</td>
</tr>
<tr>
<td>29</td>
<td>Talks about dieting/losing weight</td>
<td>Anorexia/Bulimia*</td>
</tr>
<tr>
<td>30</td>
<td>Weighs his/herself or requests to be weighed</td>
<td>Anorexia/Bulimia*</td>
</tr>
<tr>
<td>31</td>
<td>Vomits after eating (self induced/medical reasons)</td>
<td>Anorexia/Bulimia* or Swallowing Problems</td>
</tr>
<tr>
<td>32</td>
<td>Chooses to take strenuous exercise</td>
<td>Anorexia/Bulimia*</td>
</tr>
</tbody>
</table>

* Behaviours that in the general population form part of the pattern of behaviours associated with Anorexia and/or Bulimia Nervosa
4.5 PROCEDURES

4.5.1 Data Collection

Data collection took place over a period of two months (May-July) in 1998. The author met with home managers from each of the 21 residential homes in the hospital. A brief explanation of the nature and purpose of the study was provided. They were asked to distribute questionnaires to their members of staff who were responsible for co-ordinating the care of named residents within the home. (N.B: every resident within the hospital was assigned to a care co-ordinator, who was normally a qualified nurse). The care co-ordinators were asked to fill out a questionnaire on each resident under their care. A contact number for the author was given to each home manager at the time of questionnaire distribution, in order that any queries by staff could be answered. Completed questionnaires were collected two-three weeks after distribution.

4.5.2 Inter-rater Reliability

In order to check that the questionnaire had inter-rater reliability (see Results section 4.2.1), in addition to staff completion of questionnaires for each individual resident, home managers were also requested to fill out an additional five questionnaires on a random selection of residents, without consultation with other staff members. These were only used for checking the inter-rater reliability of the questionnaire and not used for analysing eating patterns and population characteristics.

4.5.3 Validity

The validity of the factorial structure of the PEQ: Section 4 (eating patterns) was measured after inter-rater reliability and factor analysis had been completed. The validity procedures are detailed in the results section 4.2.4.1.

4.6 STATISTICAL ANALYSES

All data was analysed using the Statistics Package for the Social Sciences (SPSS) version 6. Statistical analyses were performed in two parts. In part one; the reliability, validity and factor structure of the PEQ Section 4 (Eating Patterns) was assessed. Kendall’s tau b correlation was used to test for inter-rater reliability of the PEQ (chosen because questionnaire data was ordinal). A factor analysis was performed to
identify underlying constructs relating to eating patterns. Cohen’s kappa was used to test for agreement between raters used in checking the validity of the factor analysis. A Cronbach alpha was used to analyse the inter-item reliability of the PEQ, post factor analysis.

Part two of the analyses consisted of descriptive and summary statistics for all population characteristics and patterns of eating. Non-parametric statistics were used to analyse the data because the data violated the criteria for using parametric statistics (i.e.: data was not of interval measurement and was not normally distributed within the sample population). Non parametric, independent sample statistics (Kruskal Wallis 1 way ANOVAs and Mann - Whitney U Tests) were performed to analyse the relationship between patterns of eating and population characteristics. A Non parametric Friedman 2 way ANOVA for related samples was used to analyse differences between mean factor scores for eating patterns and a Spearman rank correlation was used to measure the level of association between different patterns of eating.

4.7 SCORING AND MANAGEMENT OF MISSING DATA

4.7.1 Scoring

Categorical variables (i.e. Yes/No responses) were coded as binary variables in SPSS. Ordered variables were assigned a rank score. Items measuring eating patterns were scored using the 6 point likert scale. “Non-applicable” responses were coded as 1.

4.7.2 Missing Data

The total dataset (n= 322) was used during the analysis of reliability, validity and factor structure of the Eating Patterns section of the PEQ.

Due to missing data on individual items of the PEQ (section on eating patterns), 38 cases were then deleted from the dataset for the purpose of all descriptive statistics and subsequent statistical analyses. (n= 284).
5 RESULTS

5.1 RELIABILITY, VALIDITY AND FACTOR STRUCTURE OF THE PEQ QUESTIONNAIRE

5.1.1 Inter-Rater Reliability

As described in methods section 3.5.2, for the purpose of establishing inter-rater reliability, PEQ’s were completed twice on sixty-six residents, once by their care co-ordinator (used for data analyses) and once by their Home Manager. 17 of 21 Home Managers completed an average of 4 questionnaires each (range 1-6 questionnaires).

Because the questionnaire used an ordinal scale of measurement, Kendall’s tau b (one tailed) correlation (nonparametric measure of correlation for ordinal variables) was chosen as the most appropriate measure of agreement between the two ratings.

Twenty six out of 32 questions were found to be significantly correlated between the raters (p<0.05), although three of these questions did exhibit correlation coefficients below 0.3 (Q’s 2, 23 and 31 ). Ratings for 4 questions were not significantly correlated (Questions 22, 25, 26 and 30). Correlations could not be performed on two questions (questions 4 and 32) because all the responses by the second raters, on both these questions were equal to one. The lack of variance in responses disallowed a statistical calculation of Kendall’s Tau b. However, for both question 4 and question 32, 95 % of ratings were identical, indicating a high rater agreement (Table 3). In summary, 23 questions showed acceptable inter-rater reliability with significant correlations at probability levels of 0.01 or below, 2 questions showed acceptable inter-rater reliability with 95% agreement between raters and 3 questions showed low but statistically significant inter-rater agreement at probability level 0.05. 4 questions did not show statistically significant inter-rater agreement.
TABLE 3: Inter-Rater Reliability Of Items On The PEQ As Measured By Kendall's Tau B Non-Parametric Correlation.

<table>
<thead>
<tr>
<th>Question Number</th>
<th>N †</th>
<th>Kendall's tau b Correlation Coefficient</th>
<th>Probability Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>55</td>
<td>.4531</td>
<td>***</td>
</tr>
<tr>
<td>2</td>
<td>63</td>
<td>.2658</td>
<td>*</td>
</tr>
<tr>
<td>3</td>
<td>62</td>
<td>.4785</td>
<td>***</td>
</tr>
<tr>
<td>4</td>
<td>60</td>
<td>95% agreement</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>64</td>
<td>.9214</td>
<td>***</td>
</tr>
<tr>
<td>6</td>
<td>63</td>
<td>.5767</td>
<td>***</td>
</tr>
<tr>
<td>7</td>
<td>64</td>
<td>.6464</td>
<td>***</td>
</tr>
<tr>
<td>8</td>
<td>65</td>
<td>.6843</td>
<td>***</td>
</tr>
<tr>
<td>9</td>
<td>64</td>
<td>.6297</td>
<td>***</td>
</tr>
<tr>
<td>10</td>
<td>65</td>
<td>.7069</td>
<td>***</td>
</tr>
<tr>
<td>11</td>
<td>64</td>
<td>.5284</td>
<td>***</td>
</tr>
<tr>
<td>12</td>
<td>62</td>
<td>.4956</td>
<td>***</td>
</tr>
<tr>
<td>13</td>
<td>65</td>
<td>.5923</td>
<td>***</td>
</tr>
<tr>
<td>14</td>
<td>64</td>
<td>.5558</td>
<td>***</td>
</tr>
<tr>
<td>15</td>
<td>64</td>
<td>.6569</td>
<td>***</td>
</tr>
<tr>
<td>16</td>
<td>63</td>
<td>.5434</td>
<td>***</td>
</tr>
<tr>
<td>17</td>
<td>64</td>
<td>.4683</td>
<td>***</td>
</tr>
<tr>
<td>18</td>
<td>63</td>
<td>.8389</td>
<td>***</td>
</tr>
<tr>
<td>19</td>
<td>61</td>
<td>.6688</td>
<td>***</td>
</tr>
<tr>
<td>20</td>
<td>63</td>
<td>.4594</td>
<td>***</td>
</tr>
<tr>
<td>21</td>
<td>63</td>
<td>.4763</td>
<td>***</td>
</tr>
<tr>
<td>22</td>
<td>64</td>
<td>.0471</td>
<td>-</td>
</tr>
<tr>
<td>23</td>
<td>63</td>
<td>.2847</td>
<td>*</td>
</tr>
<tr>
<td>24</td>
<td>64</td>
<td>.4316</td>
<td>***</td>
</tr>
<tr>
<td>25</td>
<td>64</td>
<td>.2030</td>
<td>-</td>
</tr>
<tr>
<td>26</td>
<td>62</td>
<td>.2293</td>
<td>-</td>
</tr>
<tr>
<td>27</td>
<td>63</td>
<td>.5849</td>
<td>***</td>
</tr>
<tr>
<td>28</td>
<td>62</td>
<td>.8238</td>
<td>***</td>
</tr>
<tr>
<td>29</td>
<td>62</td>
<td>.4432</td>
<td>**</td>
</tr>
<tr>
<td>30</td>
<td>62</td>
<td>-.0234</td>
<td>-</td>
</tr>
<tr>
<td>31</td>
<td>63</td>
<td>.2430</td>
<td>*</td>
</tr>
<tr>
<td>32</td>
<td>59</td>
<td>95% agreement</td>
<td></td>
</tr>
</tbody>
</table>

† Different values of N due to pairwise deletion of missing cases.

Kendall’s Tau B: *p<0.05; **p<0.01; ***p<0.001.

5.1.2 Factor Analysis

A factor analysis was performed on the PEQ, in order to identify any underlying constructs (due to correlations between different questionnaire items) in relation to different types of eating patterns. A principal components factor analysis with oblimin
(oblique) rotation was performed on those 28 questions of the Patterns of Eating Questionnaire that had shown acceptable inter-rater reliability. Oblimin Rotation was used as it was assumed that extracted factors would be correlated (i.e. factors would not be orthogonal).

A parallel approach to factor extraction was carried out, as detailed by Thompson and Daniel (1996). From this procedure, the data set was reduced to 6 underlying factors or constructs (see table 4 for matrix of structural co-efficients). Seven individual questionnaire items loaded significantly (i.e.: co-efficient above 0.32) on two factors.

5.1.2.1 Interpretation of Factors

The six factors were examined and each given a global label and qualifying description (table 5)

<table>
<thead>
<tr>
<th>TABLE 5: Labels And Descriptions Of Originally Extracted Factors.</th>
</tr>
</thead>
<tbody>
<tr>
<td>FACTOR I</td>
</tr>
<tr>
<td>RELUCTANT EATING</td>
</tr>
<tr>
<td>Evidences unwillingness or reluctance to eat</td>
</tr>
<tr>
<td>FACTOR II</td>
</tr>
<tr>
<td>PEOCCUPATION WITH FOOD</td>
</tr>
<tr>
<td>Desires food and/or seeks to eat or drink excessively</td>
</tr>
<tr>
<td>FACTOR III</td>
</tr>
<tr>
<td>CONCERNED WITH BODY IMAGE</td>
</tr>
<tr>
<td>Seeks to control weight and/or shape by dieting or controlling food intake</td>
</tr>
<tr>
<td>FACTOR IV</td>
</tr>
<tr>
<td>DIFFICULTIES WITH EATING</td>
</tr>
<tr>
<td>Evidences problems with chewing, swallowing and/or ingestion</td>
</tr>
<tr>
<td>FACTOR V</td>
</tr>
<tr>
<td>PICA</td>
</tr>
<tr>
<td>Ingestion of “inappropriate” foods or non-food substances</td>
</tr>
<tr>
<td>FACTOR VI</td>
</tr>
<tr>
<td>SELECTIVE EATING</td>
</tr>
<tr>
<td>Evidences fussy eating and/or chooses limited diet</td>
</tr>
</tbody>
</table>
Table 4. Structural Co-efficients Produced From A Principal Components Factor Analysis, With Oblimin Rotation and Parallel Approach to Factor Extraction.

<table>
<thead>
<tr>
<th>Questionnaire Items</th>
<th>Factor I</th>
<th>Factor II</th>
<th>Factor III</th>
<th>Factor IV</th>
</tr>
</thead>
<tbody>
<tr>
<td>Needs encouragement to eat a meal</td>
<td>0.10</td>
<td>0.03</td>
<td>0.03</td>
<td>0.03</td>
</tr>
<tr>
<td>Does my hunger restart, even after a meal?</td>
<td>0.30</td>
<td>0.05</td>
<td>0.05</td>
<td>0.05</td>
</tr>
<tr>
<td>How often do I eat before I am hungry?</td>
<td>0.30</td>
<td>0.05</td>
<td>0.05</td>
<td>0.05</td>
</tr>
<tr>
<td>How frequently do I eat to avoid feeling hungry?</td>
<td>0.30</td>
<td>0.05</td>
<td>0.05</td>
<td>0.05</td>
</tr>
<tr>
<td>Does my hunger return, even after a meal?</td>
<td>0.30</td>
<td>0.05</td>
<td>0.05</td>
<td>0.05</td>
</tr>
<tr>
<td>How often do I eat when I am not hungry?</td>
<td>0.30</td>
<td>0.05</td>
<td>0.05</td>
<td>0.05</td>
</tr>
<tr>
<td>How frequently do I eat to avoid feeling hungry?</td>
<td>0.30</td>
<td>0.05</td>
<td>0.05</td>
<td>0.05</td>
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<td>0.05</td>
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<td>0.05</td>
<td>0.05</td>
<td>0.05</td>
</tr>
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<td>0.05</td>
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<td>0.05</td>
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<td>0.05</td>
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<td>0.05</td>
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<td>0.05</td>
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<td>0.05</td>
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<td>0.05</td>
<td>0.05</td>
</tr>
<tr>
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<td>0.05</td>
<td>0.05</td>
</tr>
<tr>
<td>How often do I eat when I am not hungry?</td>
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<td>0.05</td>
<td>0.05</td>
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<td>0.05</td>
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<td>0.05</td>
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</tr>
<tr>
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<td>0.05</td>
<td>0.05</td>
<td>0.05</td>
</tr>
<tr>
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<td>0.05</td>
<td>0.05</td>
<td>0.05</td>
</tr>
<tr>
<td>How often do I eat when I am not hungry?</td>
<td>0.30</td>
<td>0.05</td>
<td>0.05</td>
<td>0.05</td>
</tr>
<tr>
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<td>0.05</td>
<td>0.05</td>
<td>0.05</td>
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<tr>
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<td>0.05</td>
<td>0.05</td>
</tr>
<tr>
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<td>0.05</td>
<td>0.05</td>
</tr>
<tr>
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<td>0.05</td>
<td>0.05</td>
<td>0.05</td>
</tr>
<tr>
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<td>0.30</td>
<td>0.05</td>
<td>0.05</td>
<td>0.05</td>
</tr>
<tr>
<td>How often do I eat when I am not hungry?</td>
<td>0.30</td>
<td>0.05</td>
<td>0.05</td>
<td>0.05</td>
</tr>
<tr>
<td>How frequently do I eat to avoid feeling hungry?</td>
<td>0.30</td>
<td>0.05</td>
<td>0.05</td>
<td>0.05</td>
</tr>
</tbody>
</table>
TABLE 4. Structural Co-Efficients From a Principal Components Factor Analysis With Oblimin Rotation and Parallel Approach to Factor Extraction

<table>
<thead>
<tr>
<th>Item</th>
<th>Factor I</th>
<th>Factor II</th>
<th>Factor III</th>
<th>Factor IV</th>
<th>Factor V</th>
<th>Factor VI</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.</td>
<td>Choose only to eat sweet and/or fatty foods</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td>Eats a varied variety of foods</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td>Avoids eating sweet and/or fatty foods</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td>Voracious eater</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.</td>
<td>Eats infrequent meals</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.</td>
<td>Uses frequent meals</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.</td>
<td>Refrains from eating</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9.</td>
<td>Likes food in his/her mouth</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

NB: Significant structural co-efficient = 0.32 or above.

Cont.
5.1.3 Validity of Factor Structures

5.1.3.1 Card Sort and Cohen's Kappa

In order to examine the content validity of the factors extracted by the factor analysis, a "card sort" procedure was carried out as follows. Four clinical psychologists in training (post learning disabilities placement), were given the 28 individual items from the PEQ (Eating Patterns) in random order and six descriptive labels (representing the six extracted factors: see table 3). Each "expert" was asked to place each of the 28 items under the most fitting or appropriate of the six labels (i.e. under which label they thought the item belonged). An extra label was provided called "Other" for items which the experts thought did not fit into any of the six labels provided or appeared to fit into more than one factor.

Level of agreement was measured for each pairing of experts using Cohen's Kappa (six pairings and six Kappa's in total). The six obtained kappa statistics ranged from 0.58 to 0.70, giving an averaged kappa statistic of 0.64 indicating significant rater agreement in classifying individual items into factors (Appendix II).

5.1.3.2 Content Validity of Individual Factor Items

The previous procedure was able to measure the level of agreement between each pairing of experts, in classifying questionnaire items into factors. However, it was unable to measure whether raters placed any given individual item into the same factor as given by the statistical factor analysis.

In order to test for the content validity of individual items on each of the 6 extracted factors, the percentage agreement between the four experts and the structural factor analysis was obtained. An agreement rate of 75% or greater (3 out of 4 experts agree) for the classification of each item, was taken to be an acceptable level of agreement between experts. A total of 8 items fell below this level.

100% of experts accurately located 15 items and 75% of experts located 5 items into the same factors, as indicated by the statistical factor analysis. The 20 items that had satisfactory agreement can be found in Table 6.
TABLE 6: Questions exhibiting content validity (agreement 75% or greater)

<table>
<thead>
<tr>
<th>FACTORS</th>
<th>QUESTIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Factor I: Reluctant Eating</td>
<td>8. Refuses to eat his/her meal</td>
</tr>
<tr>
<td></td>
<td>10. Doesn't finish his/her meal</td>
</tr>
<tr>
<td></td>
<td>11. Eats very little</td>
</tr>
<tr>
<td>Factor II: Preoccupation with</td>
<td>7. Eats a meal more quickly than others</td>
</tr>
<tr>
<td>Food</td>
<td>12. Eats more food than others</td>
</tr>
<tr>
<td></td>
<td>13. Drinks to excess</td>
</tr>
<tr>
<td></td>
<td>14. Requests food between mealtimes</td>
</tr>
<tr>
<td></td>
<td>19. Searches for food between meals</td>
</tr>
<tr>
<td></td>
<td>21. Takes food</td>
</tr>
<tr>
<td></td>
<td>24. Eats large amounts of food within a short period of time outside of</td>
</tr>
<tr>
<td></td>
<td>mealtimes</td>
</tr>
<tr>
<td>Factor III: Concern for Body</td>
<td>27. Talks about his/her weight</td>
</tr>
<tr>
<td>Image</td>
<td>28. Thinks they are fat</td>
</tr>
<tr>
<td></td>
<td>29. Talks about dieting/losing weight</td>
</tr>
<tr>
<td>Factor IV: Difficulties with</td>
<td>15. Chokes on food</td>
</tr>
<tr>
<td>Eating</td>
<td>16. Lets food sit in his/her mouth</td>
</tr>
<tr>
<td></td>
<td>17. Chews food for long periods of time</td>
</tr>
<tr>
<td></td>
<td>18. Regurgitates their food</td>
</tr>
<tr>
<td>Factor V: Pica</td>
<td>4. Eats inappropriate (i.e.: frozen or uncooked) foods</td>
</tr>
<tr>
<td></td>
<td>5. Eats inedible (non-food) objects</td>
</tr>
<tr>
<td>Factor VI: Selective Eating</td>
<td>3. Eats a limited variety of food</td>
</tr>
</tbody>
</table>

As can be seen, Factor V and VI had less than 3 items exhibiting satisfactory content validity. These factors were therefore deemed invalid and subsequently excluded from any further analyses, leaving four valid factors.

5.1.4 Inter-item Reliability on the Four Valid and Reliable Factors

At this stage of the analysis, there were 17 items for which satisfactory inter-rater reliability and content validity had been established. It was now necessary to see whether in this set of questions, satisfactory inter-item reliability could be established within each factor (so that factors could be used as additive scales to measure
proposed underlying concepts). Cronbach’s Alpha analyses (Tabachnick and Fidell, 1996) were performed on those questions within the remaining four factors. Reliable standardised Cronbach alpha coefficients (above 0.60) were achieved for all four factors/scales (Table 7). For Factor IV, one question (Q15) was found to lower the inter-item correlation of the attitude scale to below an acceptable standard of reliability (below 0.6 alpha coefficient). When this question was excluded, a reliable Cronbach alpha coefficient of 0.61 was achieved for the remaining 3 item scale.

**TABLE 7: Results Of Cronbach Alpha Analysis, Performed On Four Extracted Factor Structures From The PEQ**

<table>
<thead>
<tr>
<th>Factor</th>
<th>Number of Items</th>
<th>No. of Cases</th>
<th>Cronbach Co-efficient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Factor I: Reluctant Eating</td>
<td>3</td>
<td>319</td>
<td>0.86</td>
</tr>
<tr>
<td>Factor II: Preoccupation with Food</td>
<td>7</td>
<td>310</td>
<td>0.76</td>
</tr>
<tr>
<td>Factor III: Concerned with Body Image</td>
<td>3</td>
<td>318</td>
<td>0.88</td>
</tr>
<tr>
<td>Factor IV: Difficulties with Eating</td>
<td>3</td>
<td>315</td>
<td>0.61</td>
</tr>
</tbody>
</table>

Thus, four valid and reliable factors were extracted from the PEQ, representing four underlying concepts in relation to eating patterns or problems within a learning disabled population (Table 7). These factors were then used to obtain information on the prevalence of different eating patterns or problems within the study sample, and associations between eating patterns and other sample characteristics.

### 5.2 SAMPLE CHARACTERISTICS

#### 5.2.1 Demographics (age and gender)

Data from thirty-eight subjects were excluded from analysis, due to missing data on the PEQ, (section on eating patterns). The characteristics of 284 residents (83% of the total population) were analysed. Results are as follows: 181 (64%) residents were male and 103 (36%) female, with an age range of 21 to 95 years (mean = 50 sd = 11.91).
Table 8 details the prevalence of mental and physical health problems, behavioural problems, medication and developmental disorders within the study sample.

**TABLE 8: Mental And Physical Health Of Participating Residents**

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>Category</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental Health Problems</td>
<td>268</td>
<td>Yes</td>
<td>60</td>
<td>22.4</td>
</tr>
<tr>
<td></td>
<td></td>
<td>No</td>
<td>207</td>
<td>77.2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Don’t Know</td>
<td>1</td>
<td>0.4</td>
</tr>
<tr>
<td>Type of Mental Health Problems</td>
<td>60</td>
<td>Psychosis</td>
<td>24</td>
<td>40.0</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Affective Disorder</td>
<td>13</td>
<td>21.7</td>
</tr>
<tr>
<td></td>
<td></td>
<td>OCD</td>
<td>3</td>
<td>5.0</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Personality Disorder</td>
<td>8</td>
<td>13.3</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Other</td>
<td>4</td>
<td>6.7</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Unspecified</td>
<td>8</td>
<td>13.3</td>
</tr>
<tr>
<td>Behavioural Problems</td>
<td>277</td>
<td>No Problems</td>
<td>70</td>
<td>25.3</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mild/moderate</td>
<td>129</td>
<td>46.6</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Severe</td>
<td>78</td>
<td>28.2</td>
</tr>
<tr>
<td>Medical Problems</td>
<td>279</td>
<td>Yes</td>
<td>123</td>
<td>44.1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>No</td>
<td>156</td>
<td>55.9</td>
</tr>
<tr>
<td>Developmental Syndrome</td>
<td>270</td>
<td>Yes</td>
<td>108</td>
<td>40.0</td>
</tr>
<tr>
<td></td>
<td></td>
<td>No</td>
<td>161</td>
<td>59.6</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Don’t know</td>
<td>1</td>
<td>0.4</td>
</tr>
<tr>
<td>Autism</td>
<td>200</td>
<td>Yes</td>
<td>40</td>
<td>20.0</td>
</tr>
<tr>
<td></td>
<td></td>
<td>No</td>
<td>160</td>
<td>80.0</td>
</tr>
<tr>
<td>Medication</td>
<td>281</td>
<td>Yes</td>
<td>198</td>
<td>70.5</td>
</tr>
<tr>
<td></td>
<td></td>
<td>No</td>
<td>83</td>
<td>29.5</td>
</tr>
<tr>
<td>Contraceptive Pill</td>
<td>94</td>
<td>Yes</td>
<td>15</td>
<td>16.0</td>
</tr>
<tr>
<td></td>
<td></td>
<td>No</td>
<td>79</td>
<td>84.0</td>
</tr>
<tr>
<td>Periods (female only)</td>
<td>102</td>
<td>No periods</td>
<td>49</td>
<td>48.0</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Irregular periods</td>
<td>7</td>
<td>6.9</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Regular periods</td>
<td>37</td>
<td>36.3</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Menopausal</td>
<td>9</td>
<td>8.8</td>
</tr>
<tr>
<td>Condition of Teeth</td>
<td>282</td>
<td>Own teeth good</td>
<td>198</td>
<td>70.2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Own teeth bad</td>
<td>28</td>
<td>9.9</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Dentures</td>
<td>19</td>
<td>6.7</td>
</tr>
<tr>
<td></td>
<td></td>
<td>No teeth</td>
<td>37</td>
<td>13.1</td>
</tr>
</tbody>
</table>

A minority of the sample (22%) had a diagnosed mental health problem with the most prevalent psychiatric diagnosis being one of psychosis (40%). 74.8% of the sample exhibited behavioural problems, with 28.2% exhibiting severe behavioural difficulties. Almost half of the residents (44%) were classified as having a medical
condition, with the most prevalent diagnosis being epilepsy (68%). 71% of residents were taking medication, with the majority taking either an antipsychotic (52%) and/or an anticonvulsant (50%) medication.

5.2.3 Levels of Ability

All variables measuring levels of ability were positively correlated with each other with the exception of level of supervision and vision (p> .05, Table 9). Expressive and receptive language and level of learning disability were all highly correlated with each other (r > 0.6), suggesting that staff rating of residents’ level of learning disability (as opposed to using IQ testing) relates to residents language skills. Mobility and hand control were also highly correlated (r >0.6).

**TABLE 9: Associations between Variables Measuring Levels of Ability**

<table>
<thead>
<tr>
<th>Variables Measuring Levels of Ability</th>
<th>E.L</th>
<th>R.L</th>
<th>L.D</th>
<th>S</th>
<th>M</th>
<th>V</th>
<th>H.C</th>
</tr>
</thead>
<tbody>
<tr>
<td>Expressive Language (E.L)</td>
<td>-</td>
<td>.75***</td>
<td>.64***</td>
<td>.21***</td>
<td>.21***</td>
<td>.14*</td>
<td>.26***</td>
</tr>
<tr>
<td>Receptive Language (R.L)</td>
<td>-</td>
<td>-</td>
<td>.62***</td>
<td>.24***</td>
<td>.32***</td>
<td>.20**</td>
<td>.36***</td>
</tr>
<tr>
<td>Learning Disability (L.D)</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>.29***</td>
<td>.31***</td>
<td>.23***</td>
<td>.28***</td>
</tr>
<tr>
<td>Supervision (S)</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>.26***</td>
<td>.11</td>
<td>.16**</td>
</tr>
<tr>
<td>Mobility (M)</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>.27***</td>
<td>.62***</td>
</tr>
<tr>
<td>Vision (V)</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>.24***</td>
</tr>
<tr>
<td>Hand Control (H.C)</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

Spearman Rank Correlations: *p<0.05; **p<0.01; ***p<0.001.

Frequency data regarding residents’ level of language, learning disability, motor and sensory abilities are detailed in table 10. The majority of residents were classified as having a severe/profound learning disability (74%). There was a mixed range of expressive and receptive language skills across the sample population. The majority of the population had good mobility (62 %), no visual impairments (85%), or no hand control problems (78%). 46% of the sample population required extra staff input or one to one supervision.
### TABLE 10: Residents Characteristics In Relation To Levels Of Ability

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>Category</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Expressive Language</strong></td>
<td>283</td>
<td>No spoken language</td>
<td>102</td>
<td>36.0</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Signing</td>
<td>10</td>
<td>3.5</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Echoes</td>
<td>8</td>
<td>2.8</td>
</tr>
<tr>
<td></td>
<td></td>
<td>One word</td>
<td>16</td>
<td>5.7</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Two-three words</td>
<td>61</td>
<td>21.6</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Full sentences</td>
<td>86</td>
<td>30.4</td>
</tr>
<tr>
<td><strong>Receptive Language</strong></td>
<td>278</td>
<td>Little/no understanding</td>
<td>51</td>
<td>18.3</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Gestures only</td>
<td>4</td>
<td>1.4</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Single commands</td>
<td>83</td>
<td>29.9</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Sequence of two commands</td>
<td>32</td>
<td>11.5</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Range of instructions</td>
<td>108</td>
<td>38.8</td>
</tr>
<tr>
<td><strong>Level of Learning</strong></td>
<td>276</td>
<td>Profound-</td>
<td>46</td>
<td>15.2</td>
</tr>
<tr>
<td>Disability</td>
<td></td>
<td>Severe-</td>
<td>163</td>
<td>59.1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Moderate-</td>
<td>38</td>
<td>13.8</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mild-</td>
<td>33</td>
<td>12.0</td>
</tr>
<tr>
<td><strong>Mobility</strong></td>
<td>280</td>
<td>Non-mobile-</td>
<td>60</td>
<td>21.4</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Aided-</td>
<td>43</td>
<td>15.4</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Walks unaided-</td>
<td>177</td>
<td>62.3</td>
</tr>
<tr>
<td><strong>Vision</strong></td>
<td>276</td>
<td>Severe visual impairment</td>
<td>21</td>
<td>7.6</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Limited sight-</td>
<td>21</td>
<td>7.6</td>
</tr>
<tr>
<td></td>
<td></td>
<td>No visual impairment</td>
<td>234</td>
<td>84.8</td>
</tr>
<tr>
<td><strong>Hand Control Problems</strong></td>
<td>275</td>
<td>Severe problems-</td>
<td>30</td>
<td>10.9</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mild/moderate problems-</td>
<td>32</td>
<td>11.6</td>
</tr>
<tr>
<td></td>
<td></td>
<td>No problems-</td>
<td>213</td>
<td>77.5</td>
</tr>
<tr>
<td><strong>Level of Supervision</strong></td>
<td>281</td>
<td>One to one</td>
<td>79</td>
<td>28.1</td>
</tr>
<tr>
<td>Needed.</td>
<td></td>
<td>Some extra help</td>
<td>51</td>
<td>18.1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Normal staff input</td>
<td>151</td>
<td>53.7</td>
</tr>
</tbody>
</table>

#### 5.2.4 Feeding, Diets and Weight

The weight status of each individual resident was established using Body Mass Index (BMI = weight (kg) / height (metres)²). According to classifications of weight status, based on BMI Scores (World Health Organization), the majority of residents were of normal or ideal weight. 9.5% were classified as obese and 6.8 % were classified as being underweight (Table 11).
TABLE 11: Subjects Weight Status As Classified By Body Mass Index.

<table>
<thead>
<tr>
<th>BMI scores</th>
<th>N</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Severely Underweight</td>
<td>2</td>
<td>0.8</td>
</tr>
<tr>
<td>Underweight</td>
<td>15</td>
<td>6.0</td>
</tr>
<tr>
<td>Normal</td>
<td>129</td>
<td>51.2</td>
</tr>
<tr>
<td>Overweight</td>
<td>82</td>
<td>32.5</td>
</tr>
<tr>
<td>Obese</td>
<td>24</td>
<td>9.5</td>
</tr>
<tr>
<td>Total</td>
<td>252</td>
<td></td>
</tr>
</tbody>
</table>

The majority of residents were able to feed themselves (222; 81%). 84 (33%) were on special diets. Of those residents on diets, 42% were on weight loss diets, 21% were on weight gain diets, 19% were on soft diets and 9% were on high fibre diets. 47% of underweight residents were on weight gain diets. 85% of overweight residents were on weight loss diets. Of those 129 residents classified as having normal weight, 40% were on weight gain and 15% were on weight loss diets.

5.3 PATTERNS OF EATING

5.3.1 Prevalence of Eating Patterns

Within each factor, the mean score for each resident was calculated. In addition non food pica was measured using scores from one questionnaire item (Question 5: Eats inedible (non food) objects). Table 12 summaries the mean scores, standard deviations and range of scores for each type of eating pattern. There is a significant difference between the mean scores for different eating patterns in the sample population (p<0.001). Reluctance to eat showed the highest mean score and concerns for body image had the lowest mean score.

TABLE 12: Means, Standard Deviations and Range of scores for Eating Patterns

<table>
<thead>
<tr>
<th>Eating Patterns</th>
<th>Mean Scores</th>
<th>Standard Deviations</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reluctance to eat</td>
<td>1.78***</td>
<td>.88</td>
<td>1 - 4.33</td>
</tr>
<tr>
<td>Preoccupation with food</td>
<td>1.44</td>
<td>.60</td>
<td>1 - 4.71</td>
</tr>
<tr>
<td>Concerned with body image</td>
<td>1.19</td>
<td>.56</td>
<td>1 - 4.67</td>
</tr>
<tr>
<td>Difficulties with eating</td>
<td>1.27</td>
<td>.61</td>
<td>1 - 4.67</td>
</tr>
<tr>
<td>Non-Food Pica</td>
<td>1.26</td>
<td>.82</td>
<td>1 - 6</td>
</tr>
</tbody>
</table>

Friedman Two Way Anova *p<0.05; **p<0.01; ***p<0.001.
Table 13 summaries the frequency and percentage of residents evidencing difficult eating patterns. The *mean* percentage of residents exhibiting each eating pattern were derived by averaging percentages for individual factor items. A mean of 30% of residents exhibited a reluctance to eat and a mean of 15% of residents exhibited preoccupation for food. A smaller mean percentage of residents exhibited concerns about their body image (7%). 9% of residents had some difficulties with chewing and swallowing. 10% of residents exhibited pica at least some of the time.

5.3.2 *Relationships between Eating Patterns.*

Table 14 shows the correlations between different patterns of eating. There were significant positive correlations between 1) reluctance to eat and difficulties eating ($p<0.001$) 2) reluctance to eat and preoccupation with food ($p<0.01$) 3) preoccupation with food and pica ($p<0.01$) and 4) preoccupation with food and concerns for body image ($p<0.05$).
TABLE I: Total and Mean Frequencies Of Residents Eating Patterns.

<table>
<thead>
<tr>
<th>Factor: I: Preoccupation with Food</th>
<th>Never/Seldom</th>
<th>Sometimes</th>
<th>Often/Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>Resident Mean % of Residens (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No. of Residents</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Evidence of some difficulties</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Factor Items</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Evidence Some Difficulties</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total (% of Residents)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No of Residents</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Evidence of some difficulties</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

TABLE II: Differences with Eating

<table>
<thead>
<tr>
<th>Factor: II: Concern for Body Image</th>
<th>69%</th>
<th>96%</th>
<th>70%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Takes a meal quickly, more often</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Takes less food between meals</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Likes to snack</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Takes larger amounts of food when short</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Takes less food when hungry</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

TABLE III: Differences with Eating

<table>
<thead>
<tr>
<th>Factor: III: Differences in Eating</th>
<th>96%</th>
<th>70%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eats very little</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Doesn't finish his/her meal</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prefers to eat his/her meal</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prefers to eat less</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prefers to eat more</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

TABLE IV: Differences with Eating

<table>
<thead>
<tr>
<th>Factor: IV: Difficulties with Eating</th>
<th>96%</th>
<th>70%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chews food for long periods of time</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lets food slip in his/her mouth</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Resolves their food</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Takes about chewing foods including weight</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Takes about his/her weight</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

TABLE V: Differences with Eating

<table>
<thead>
<tr>
<th>Factor: V: Difficulties with Eating</th>
<th>96%</th>
<th>70%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eats more food than others</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eats a meal quickly, more often</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prefers to eat his/her meal</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prefers to eat less</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prefers to eat more</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

TABLE VI: Differences with Eating

<table>
<thead>
<tr>
<th>Factor: VI: Difficulties with Eating</th>
<th>96%</th>
<th>70%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eats very little</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Doesn't finish his/her meal</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prefers to eat his/her meal</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prefers to eat less</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prefers to eat more</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

TABLE VII: Differences with Eating

<table>
<thead>
<tr>
<th>Factor: VII: Difficulties with Eating</th>
<th>96%</th>
<th>70%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eats very little</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Doesn't finish his/her meal</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prefers to eat his/her meal</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prefers to eat less</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prefers to eat more</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**TABLE 14: Associations between Eating Patterns**

<table>
<thead>
<tr>
<th>Interrelationships of Eating Patterns</th>
<th>No. Ss</th>
<th>Reluctance to eat</th>
<th>Preoccupation with food</th>
<th>Concerned with body image</th>
<th>Difficulties with eating</th>
<th>Non-Food Pica</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reluctance to Eat</td>
<td>284</td>
<td>-</td>
<td>.17***</td>
<td>.05</td>
<td>.24***</td>
<td>.12</td>
</tr>
<tr>
<td>Preoccupation with Food</td>
<td>284</td>
<td>-</td>
<td>.13*</td>
<td>.10</td>
<td>.16**</td>
<td></td>
</tr>
<tr>
<td>Concerned with Body Image</td>
<td>284</td>
<td>-</td>
<td>-</td>
<td>-.07</td>
<td>-.06</td>
<td></td>
</tr>
<tr>
<td>Difficulties with Eating</td>
<td>284</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>.07</td>
<td></td>
</tr>
<tr>
<td>Non-Food Pica</td>
<td>284</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Spearman Rank Correlations: *p<0.05; **p<0.01; ***p<0.001.

5.4 POPULATION CHARACTERISTICS AND ASSOCIATED PATTERNS OF EATING

5.4.1 Age and gender

Table 15 summarises the relationship of eating patterns with residents’ gender. Table 16 summaries the relationship of eating patterns with residents’ age.

Female residents showed a greater reluctance to eat and had more concerns about body image, compared to male residents (p<0.05).

There was a small but significant correlation between age and pica (p<0.05). Pica was greater for younger residents and tended to reduce with increasing age.

**TABLE 15  Relationship Of Eating Patterns To Gender**

<table>
<thead>
<tr>
<th>Gender</th>
<th>No. Ss</th>
<th>Reluctance to eat</th>
<th>Preoccupation with food</th>
<th>Concerned with body image</th>
<th>Difficulties with eating</th>
<th>Non-Food Pica</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Mean Scores</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>181</td>
<td>5.1</td>
<td>10.0</td>
<td>3.37</td>
<td>3.86</td>
<td>1.25</td>
</tr>
<tr>
<td>Female</td>
<td>103</td>
<td>5.8*</td>
<td>10.3</td>
<td>3.89*</td>
<td>3.75</td>
<td>1.29</td>
</tr>
</tbody>
</table>

Mann Whitney Nonparametric Test: *p<0.05; **p<0.01; ***p<0.001.
**TABLE 16  Relationship Of Eating Patterns To Age.**

<table>
<thead>
<tr>
<th>No. Ss</th>
<th>Reluctance to eat</th>
<th>Preoccupation with food</th>
<th>Concerned with body image with eating</th>
<th>Difficulties with eating</th>
<th>Non-Food Pica</th>
<th>Correlation Co-efficients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Spearman Rank Correlation Nonparametric Tests: *p&lt;0.05; **p&lt;0.01; ***p&lt;0.001.</td>
</tr>
<tr>
<td>268</td>
<td>.001</td>
<td>-.04</td>
<td>-.05</td>
<td>-.12</td>
<td>-.15*</td>
<td></td>
</tr>
</tbody>
</table>

5.4.2 Mental and Physical Health and Medication

Table 17 summarises the relationship of eating patterns in the sample population to mental and physical health, medication, autism and behavioural problems.

There were significant difference between residents who had mental health problems or not, and certain eating patterns. Residents, who were classified as having any type of mental health problem, exhibited more reluctance to eat (p<0.001), greater preoccupation with food (p<0.001) and greater concerns with body image (p<0.001), compared to residents with no mental health problems.

Residents on any form of medication had greater difficulties with eating (p<0.05) and higher frequency of pica (p<0.05) compared to residents who were not on any medication. There was a significant difference in mean scores for preoccupation with food for residents on different types of medication (p<0.05). Residents on anti-psychotic medication and other psychotropic drugs (anti-depressants and anxiolitics) tended to exhibit a higher frequency for preoccupation with food compared to residents on other types of medication.

Residents with autism showed a greater preoccupation for food (p<0.001) and a higher incidence of pica (p<0.001).

Residents with any medical problems showed a reduced frequency for preoccupation with food (p<0.05). Residents with anaemia or Parkinson’s disease showed a greater preoccupation with food compared to residents with epilepsy and hepatitis (Mann Whitney U tests; p < 0.05) and a greater reluctance to eat, compared to residents with epilepsy, hypothyroidism and hypertension (Mann Whitney U tests; p < 0.05).

Mean scores for reluctance to eat was higher in residents who had experienced an acute illness over the last 6 months (p<0.001).
Residents with dentures exhibited greater concerns about body image (p<0.01).
Female residents on contraceptive medication exhibited greater preoccupation with
food (p<0.05) and pica (p<0.05) compared to those who were not on
contraception.
**TABLE 17: Relationship of Eating Patterns to Medical and Psychiatric Status.**

**Medication**

<table>
<thead>
<tr>
<th>Medical/Psychiatric Characteristics</th>
<th>No. Ss</th>
<th>Reluctance to eat</th>
<th>Preoccupation with food</th>
<th>Concerned body image</th>
<th>Difficulties with eating</th>
<th>Pica</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mental Health Problems</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>All mental health problems</td>
<td>60</td>
<td>6.3***</td>
<td>11.6***</td>
<td>4.3***</td>
<td>3.7</td>
<td>1.4</td>
</tr>
<tr>
<td>No mental health problems</td>
<td>207</td>
<td>5.3</td>
<td>9.5</td>
<td>3.4</td>
<td>3.9</td>
<td>1.2</td>
</tr>
<tr>
<td>Psychosis</td>
<td>24</td>
<td>6.6</td>
<td>11.2</td>
<td>5.1</td>
<td>3.6</td>
<td>1.3</td>
</tr>
<tr>
<td>Affective disorders</td>
<td>13</td>
<td>6.2</td>
<td>13.0</td>
<td>4.1</td>
<td>3.5</td>
<td>1.3</td>
</tr>
<tr>
<td>OCD</td>
<td>3</td>
<td>8.7</td>
<td>14.0</td>
<td>5.7</td>
<td>4.0</td>
<td>1.7</td>
</tr>
<tr>
<td>Personality disorder</td>
<td>8</td>
<td>5.6</td>
<td>9.4</td>
<td>3.1</td>
<td>3.1</td>
<td>1.0</td>
</tr>
<tr>
<td>Other</td>
<td>4</td>
<td>6.8</td>
<td>12.0</td>
<td>3.0</td>
<td>5.5</td>
<td>1.5</td>
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<td>11.4</td>
<td>3.5</td>
<td>3.6</td>
<td>1.4</td>
</tr>
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<td><strong>Medication</strong></td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>All medications</td>
<td>198</td>
<td>5.5</td>
<td>10.3</td>
<td>3.7</td>
<td>3.9*</td>
<td>1.3*</td>
</tr>
<tr>
<td>No medications</td>
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<td>9.6</td>
<td>3.3</td>
<td>3.5*</td>
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<tr>
<td>Anti-psychotics</td>
<td>103</td>
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<td>11.2*</td>
<td>3.9</td>
<td>4.1</td>
<td>1.4</td>
</tr>
<tr>
<td>Anti-convulsants</td>
<td>99</td>
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<td>9.8</td>
<td>3.5</td>
<td>3.9</td>
<td>1.3</td>
</tr>
<tr>
<td>Other psychotropics</td>
<td>34</td>
<td>5.9</td>
<td>11.7</td>
<td>4.8</td>
<td>3.8</td>
<td>1.5</td>
</tr>
<tr>
<td>Iron Supplements</td>
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<td>6.5</td>
<td>9.0</td>
<td>3.3</td>
<td>4.1</td>
<td>1.5</td>
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<td>Laxatives</td>
<td>14</td>
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<td>9.8</td>
<td>3.9</td>
<td>3.3</td>
<td>1.0</td>
</tr>
<tr>
<td>Thyroxine</td>
<td>6</td>
<td>4.0</td>
<td>8.2</td>
<td>3.0</td>
<td>3.3</td>
<td>1.3</td>
</tr>
<tr>
<td>Other</td>
<td>12</td>
<td>6.8</td>
<td>9.3</td>
<td>4.0</td>
<td>3.3</td>
<td>1.7</td>
</tr>
<tr>
<td><strong>Autism</strong></td>
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<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Yes</td>
<td>40</td>
<td>5.9</td>
<td>13.5***</td>
<td>3.4</td>
<td>3.7</td>
<td>1.7**</td>
</tr>
<tr>
<td>No</td>
<td>160</td>
<td>5.3</td>
<td>9.7</td>
<td>3.7</td>
<td>4.4</td>
<td>1.2</td>
</tr>
<tr>
<td><strong>Medical Problems</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>All medical problems</td>
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<td>9.4*</td>
<td>3.5</td>
<td>3.8</td>
<td>1.3</td>
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<tr>
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<td>5.3</td>
<td>10.4</td>
<td>3.6</td>
<td>3.9*</td>
<td>1.3</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>84</td>
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<td>9.1</td>
<td>3.5</td>
<td>3.8</td>
<td>1.3</td>
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<tr>
<td>Hypertension/Heart Disease</td>
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<td>5.8</td>
<td>7.9</td>
<td>4.0</td>
<td>3.2</td>
<td>1.5</td>
</tr>
<tr>
<td>Hypothyroidism</td>
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<td>8.3</td>
<td>3.0</td>
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<td>1.3</td>
</tr>
<tr>
<td>Hepatitis</td>
<td>6</td>
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<td>9.5</td>
<td>3.5</td>
<td>3.7</td>
<td>1.0</td>
</tr>
<tr>
<td>Anaemia</td>
<td>5</td>
<td>7.6*</td>
<td>14.8*</td>
<td>4.2</td>
<td>3.4</td>
<td>1.4</td>
</tr>
<tr>
<td>Parkinson's</td>
<td>2</td>
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<td>12.5*</td>
<td>3.0</td>
<td>3.5</td>
<td>1.0</td>
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<tr>
<td>Other</td>
<td>25</td>
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<td>4.0</td>
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<td>1.2</td>
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<tr>
<td><strong>Bodily Illness over last 6 months</strong></td>
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</tr>
<tr>
<td>Yes</td>
<td>21</td>
<td>7.0***</td>
<td>9.9</td>
<td>3.9</td>
<td>4.2</td>
<td>1.2</td>
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<tr>
<td>No</td>
<td>250</td>
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<td>1.3</td>
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<tr>
<td><strong>Contraceptive Pill</strong></td>
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<tr>
<td>Yes</td>
<td>15</td>
<td>5.6</td>
<td>11.3*</td>
<td>5.3</td>
<td>3.6</td>
<td>1.9**</td>
</tr>
<tr>
<td>No</td>
<td>79</td>
<td>5.8</td>
<td>9.6</td>
<td>3.6</td>
<td>3.8</td>
<td>1.2</td>
</tr>
<tr>
<td><strong>Teeth</strong></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Own Teeth Good</td>
<td>198</td>
<td>5.3</td>
<td>10.2</td>
<td>3.6</td>
<td>3.8</td>
<td>1.3</td>
</tr>
<tr>
<td>Own Teeth Bad</td>
<td>28</td>
<td>6.0</td>
<td>10.3</td>
<td>3.4</td>
<td>3.5</td>
<td>1.3</td>
</tr>
<tr>
<td>Dentures</td>
<td>19</td>
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<td>9.9</td>
<td>4.4**</td>
<td>3.4</td>
<td>1.1</td>
</tr>
<tr>
<td>No Teeth</td>
<td>37</td>
<td>5.2</td>
<td>9.3</td>
<td>3.2</td>
<td>4.3</td>
<td>1.2</td>
</tr>
</tbody>
</table>

*Mann Whitney U & Kruskal Wallis Nonparametric Tests: *p<0.05; **p<0.01; ***p<0.001.*
5.4.3 **Levels of Ability**

Table 18 summarises mean scores for eating patterns for different levels of behavioural problems, physical and cognitive abilities. Higher scores indicate a greater frequency of the eating pattern.

**TABLE 18: Mean Scores for Eating Patterns for different levels of Behavioural Problems, Physical Abilities and Cognitive Status**

<table>
<thead>
<tr>
<th>Levels of behavioural problems, physical and cognitive abilities</th>
<th>No. Ss</th>
<th>Reluctance to eat</th>
<th>Preoccupation with food</th>
<th>Concerned body image</th>
<th>Difficulties with eating</th>
<th>Pica</th>
</tr>
</thead>
<tbody>
<tr>
<td>Behavioural Problems</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No Problems</td>
<td>70</td>
<td>4.8</td>
<td>8.5</td>
<td>3.3</td>
<td>3.7</td>
<td>1.1</td>
</tr>
<tr>
<td>Mild/Moderate Problems</td>
<td>129</td>
<td>5.5</td>
<td>10.2</td>
<td>3.7</td>
<td>3.7</td>
<td>1.2</td>
</tr>
<tr>
<td>Severe Problems</td>
<td>78</td>
<td>5.5</td>
<td>11.6</td>
<td>3.6</td>
<td>4.1</td>
<td>1.6</td>
</tr>
<tr>
<td>Level of Learning Disability</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild</td>
<td>33</td>
<td>5.8</td>
<td>10.5</td>
<td>5.0</td>
<td>3.2</td>
<td>1.2</td>
</tr>
<tr>
<td>Moderate</td>
<td>38</td>
<td>6.3</td>
<td>11.5</td>
<td>4.3</td>
<td>3.6</td>
<td>1.1</td>
</tr>
<tr>
<td>Severe</td>
<td>163</td>
<td>5.3</td>
<td>10.1</td>
<td>3.2</td>
<td>3.8</td>
<td>1.4</td>
</tr>
<tr>
<td>Profound</td>
<td>42</td>
<td>4.6</td>
<td>8.4</td>
<td>3.1</td>
<td>4.4</td>
<td>1.1</td>
</tr>
<tr>
<td>Level of Supervision Needed</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Normal staff input</td>
<td>151</td>
<td>5.2</td>
<td>9.8</td>
<td>3.7</td>
<td>3.6</td>
<td>1.2</td>
</tr>
<tr>
<td>Extra help</td>
<td>51</td>
<td>6.0</td>
<td>10.8</td>
<td>3.6</td>
<td>3.9</td>
<td>1.4</td>
</tr>
<tr>
<td>One to one</td>
<td>79</td>
<td>5.2</td>
<td>10.0</td>
<td>3.4</td>
<td>4.2</td>
<td>1.3</td>
</tr>
<tr>
<td>Mobility</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Walks unaided</td>
<td>177</td>
<td>5.2</td>
<td>10.6</td>
<td>3.6</td>
<td>3.9</td>
<td>1.4</td>
</tr>
<tr>
<td>Walks with aids</td>
<td>43</td>
<td>6.1</td>
<td>10.1</td>
<td>3.5</td>
<td>3.3</td>
<td>1.1</td>
</tr>
<tr>
<td>Non-mobile</td>
<td>60</td>
<td>5.2</td>
<td>8.5</td>
<td>3.5</td>
<td>3.9</td>
<td>1.2</td>
</tr>
<tr>
<td>Vision</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No visual impairments</td>
<td>232</td>
<td>5.2</td>
<td>10.3</td>
<td>3.6</td>
<td>3.8</td>
<td>1.3</td>
</tr>
<tr>
<td>Limited sight</td>
<td>21</td>
<td>6.4</td>
<td>8.7</td>
<td>3.7</td>
<td>3.8</td>
<td>1.2</td>
</tr>
<tr>
<td>Severe visual impairment</td>
<td>21</td>
<td>5.9</td>
<td>8.1</td>
<td>3.0</td>
<td>4.5</td>
<td>1.0</td>
</tr>
<tr>
<td>Hand-control problems</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No problems</td>
<td>213</td>
<td>5.4</td>
<td>10.5</td>
<td>3.6</td>
<td>3.8</td>
<td>1.3</td>
</tr>
<tr>
<td>Mild/moderate difficulties</td>
<td>32</td>
<td>5.2</td>
<td>9.1</td>
<td>3.7</td>
<td>3.7</td>
<td>1.1</td>
</tr>
<tr>
<td>Severe difficulties</td>
<td>30</td>
<td>5.2</td>
<td>7.3</td>
<td>3.3</td>
<td>4.1</td>
<td>1.0</td>
</tr>
</tbody>
</table>
Table 19 summarises the statistical relationship between eating patterns and residents' level of ability.

**TABLE 19: Associations between Eating Patterns and Levels of Behavioural Problems, Physical Abilities and Cognitive Status**

<table>
<thead>
<tr>
<th>Levels of Ability (Scores from ordinal scaled items)</th>
<th>Mean Scores</th>
<th>Correlation co-efficients</th>
</tr>
</thead>
<tbody>
<tr>
<td>No. Ss</td>
<td>Reluctance to eat</td>
<td>Preoccupation with food</td>
</tr>
<tr>
<td>Behavioural Problems</td>
<td>-08</td>
<td>-.32***</td>
</tr>
<tr>
<td>Level of Learning Disability</td>
<td>.18**</td>
<td>.25***</td>
</tr>
<tr>
<td>Level of Supervision Needed</td>
<td>-.02</td>
<td>-.04</td>
</tr>
<tr>
<td>Mobility</td>
<td>-.03</td>
<td>.26***</td>
</tr>
<tr>
<td>Vision</td>
<td>-.12*</td>
<td>.18**</td>
</tr>
<tr>
<td>Hand-control problems</td>
<td>.03</td>
<td>.29***</td>
</tr>
</tbody>
</table>

Spearman Rank Non-Parametric Correlation's: *p<0.05; **p<0.01; ***p<0.001.

There was a significant correlation between level of behavioural problems and a) preoccupation for food (p<0.001) and b) pica (p<0.001). Preoccupation with food and frequency of pica was greater for residents with increasing severity of behavioural difficulties.

There were significant relationships between certain patterns of eating and residents' level of learning disability. There was a significant correlation between level of learning disability and a) reluctance to eat (p<0.01) b) preoccupation with food (p<0.001) and c) concerns for body image (p<0.001). There was a significant correlation between level of learning disability and difficulties with eating (p<0.05). Residents who had milder learning disabilities exhibited greater reluctance to eat, greater preoccupation with food, more concerns about body image and less difficulty with eating, compared to residents with more severe learning disabilities.

There was a statistically significant correlation between levels of staff supervision and difficulties with eating (p<0.01). Residents, who required greater levels of staff supervision, exhibited more difficulties with eating.
There was a significant correlation between level of mobility and preoccupation with food (p<0.001). Residents who were more mobile exhibited greater preoccupation with food compared to residents with limited or no mobility.

There was significant correlation between level of visual ability and a) reluctance to eat (p<0.05) and b) preoccupation with food (p<0.01). Residents with visual disability exhibited greater reluctance to eat and less preoccupation with food compared to residents with better vision.

There was a significant correlation between hand control and preoccupation with food (p<0.001). Residents with better hand control exhibited greater preoccupation with food.

5.4.4 Diets, Weight and Patterns of Eating

Table 20 summarises the relationship between eating patterns, diets and ability to feed. Table 21 summarises the relationship between eating patterns and weight status.

**TABLE 20: Relationship of Eating Patterns to Dieting and Feeding**

<table>
<thead>
<tr>
<th>Diets and Feeding</th>
<th>No. Ss</th>
<th>Reluctance to eat</th>
<th>Preoccupation with food</th>
<th>Concerned body image</th>
<th>Difficulties with eating</th>
<th>Pica</th>
</tr>
</thead>
<tbody>
<tr>
<td>Special Diet</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>All Diets</td>
<td>84</td>
<td>5.21</td>
<td>10.50</td>
<td>4.17***</td>
<td>3.63</td>
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<td>No Diet</td>
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<td>5.30</td>
<td>9.89</td>
<td>3.32</td>
<td>3.98</td>
<td>1.29</td>
</tr>
<tr>
<td>Weight gain</td>
<td>17</td>
<td>7.00*</td>
<td>10.65</td>
<td>3.53**</td>
<td>4.12*</td>
<td>1.29</td>
</tr>
<tr>
<td>Weight loss</td>
<td>34</td>
<td>4.24</td>
<td>11.59</td>
<td>5.32</td>
<td>3.09</td>
<td>1.09</td>
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<tr>
<td>High fibre</td>
<td>7</td>
<td>6.14</td>
<td>10.86</td>
<td>3.00</td>
<td>4.00</td>
<td>1.00</td>
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<td>5.33</td>
<td>9.13</td>
<td>3.27</td>
<td>3.87</td>
<td>1.27</td>
</tr>
<tr>
<td>Other</td>
<td>8</td>
<td>5.13</td>
<td>8.75</td>
<td>3.75</td>
<td>4.00</td>
<td>1.25</td>
</tr>
<tr>
<td>Feeding</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self feeding</td>
<td>222</td>
<td>5.47</td>
<td>10.53***</td>
<td>3.69*</td>
<td>3.73</td>
<td>1.28</td>
</tr>
<tr>
<td>Assisted feeding</td>
<td>53</td>
<td>4.79</td>
<td>8.26</td>
<td>3.11</td>
<td>4.32*</td>
<td>1.19</td>
</tr>
</tbody>
</table>

*Mann Whitney U and Kruskal Wallis Nonparametric Tests: *p<0.05; **p<0.01; ***p<0.001.*
TABLE 21: Relationship of Eating Patterns to Weight

<table>
<thead>
<tr>
<th>Weight</th>
<th>No. Ss</th>
<th>Reluctance to eat</th>
<th>Preoccupation with food</th>
<th>Concerned body image</th>
<th>Difficulties with eating</th>
<th>Pica</th>
</tr>
</thead>
<tbody>
<tr>
<td>Weight Status</td>
<td>252</td>
<td>-.20**</td>
<td>.18**</td>
<td>.32***</td>
<td>-0.09</td>
<td>-0.03</td>
</tr>
<tr>
<td>Weight Loss</td>
<td>263</td>
<td>.15*</td>
<td>.06</td>
<td>.12*</td>
<td>-0.02</td>
<td>-0.08</td>
</tr>
<tr>
<td>Weight Gain</td>
<td>257</td>
<td>.02</td>
<td>-.05</td>
<td>.05</td>
<td>.05</td>
<td>-.05</td>
</tr>
</tbody>
</table>

Spearman Rank Non-Parametric Correlation’s : */p<0.05; **p<0.01; ***p<0.001.

Residents who were on any sort of diet exhibited greater concern for body image, compared to residents who were not on any diet (p<0.001). In particular, residents on weight loss diets exhibited the greatest amount of concern about body image (p<0.01). There was a significant difference between residents on different types of diets and mean scores for reluctance to eat and difficulties with eating (p<0.05). Residents on weight gain diets showed the most reluctance to eat and difficulties with eating. Residents on weight loss diets showed the least reluctance to eat and least difficulties with eating.

There were significant correlation’s between residents weight and a) reluctance to eat (p<0.01) b) preoccupation with food (p<0.01) and concerns about body image (p<0.001). Residents who were underweight showed the greatest reluctance to eat. Residents who were classified as overweight or obese were more preoccupied with food and more concerned about body image.

There was significant correlation between the amount of weight lost by residents over the last 6 months and a) reluctance to eat (p<0.05) and b) concern about body image (P<0.05). Residents who had lost a moderate to severe amount of weight exhibited higher mean scores for reluctance to eat and concerns about body image compared to residents who lost a slight amount of weight or no weight at all.

Residents who were able to self-feed showed greater preoccupation with food (p<0.001) and concern for body image (p<0.05) compared to residents who were assisted in feeding. Those who were assisted in feeding, exhibited greater difficulties with eating (swallowing and chewing; p<0.05).
6 DISCUSSION

There are a number of methodological limitations in this study, which indicates that caution needs to exercised when drawing conclusions from the results produced. Methodological problems particularly relate to the limited reliability and construct validity of the PEQ, and the possibility of subjective interpretation of some items on the questionnaire. The correlational nature of the study also precludes inferences of causality between statistically associated variables.

Despite the methodological problems, an instrument for measuring eating patterns and associated population characteristics was developed and piloted and moderate reliability and validity established. A whole population survey was undertaken, with good participant response rate, and contributed to previous attempts to measure types and prevalence of eating patterns in PLD.

A range of eating patterns were identified by the PEQ, which seemed to support the hypothesis (HI) that a range of eating patterns do exist within this population. The eating patterns found included: *Reluctance to Eat*, defined as refusing to finish meals, not finishing meals and eating very little; *Preoccupation with Food*, defined as searching and requesting food between mealtimes, eating more food than others, taking food, eating large amounts of food in short periods of time and eating more quickly than others; *Concern for Body Image*, defined as talking about weight, dieting and losing weight and thoughts about being fat; *Difficulties with Eating*, defined as letting food sit in the mouth, chewing for long periods of time, and regurgitation; *Pica*, defined as ingestion of non-food substances.

These eating patterns are similar to those found in other population studies of PLD. "Reluctance to Eat" is similar in meaning to "anorexia" as measured by Danford and Huber (1981), reflecting a lack of appetite for food and a need for others to encourage food consumption. "Preoccupation for Food", is comparable in meaning and context to "hyperphagia", as measured by Danford and Huber (1981). "Difficulties with Eating" could incorporate such problems as dysphagia, regurgitation and rumination or alternatively could be a behavioural manifestation of loss of appetite and reluctance
to eat. The ambiguity of this eating pattern indicates that care is needed in its interpretation.

"Concern for Body Image", is not strictly an eating pattern but may affect the eating behaviour and weight of people with learning disabilities. The behaviours it encompasses haven’t been identified or studied extensively in this population. The prevalence of pica, on the other hand, has been well established for this population (Tewari et al, 1995; McAlpine and Singh, 1986).

6.1 PREVALENCE OF EATING PATTERNS

The most prevalent eating pattern in the sample population was reluctance to eat (30% of residents). Concern about body image was the least prevalent pattern (7% of residents). 15% exhibited preoccupation for food. 9% of the population had difficulties with eating and 10% exhibited pica. These figures seem to indicate that eating disturbances within this population are prevalent enough to warrant further research and clinical attention, particularly in relation to exploration of etiological factors and development and application of prevention and treatment interventions.

The prevalence of eating patterns found in the current study is consistent with other studies of the prevalence of eating patterns in learning disabled populations, particularly in relation to the prevalence of pica (9-10%; Tewari et al, 1995; McAlpine and Singh, 1986). Reluctance to eat (anorexia as defined by Danford and Huber) was far less prevalent and preoccupation for food (hyperphagia as defined by Danford and Huber) was much more prevalent in Danford and Huber’s population study, than indicated in the current study.

42% of residents were overweight or obese according to Body Mass Index figures. This is a far higher proportion of overweight residents, than found in Danford and Huber’s population study (29%). Other studies have found more comparable rates of overweight and obesity (Fox and Rotatori, 1982 (37.3%); Rimmer et al, 1993 (41.3%)). Almost 7% of the sample population were underweight and this figure is far lower than that found by Danford and Huber (30%). The differences in weight status
between Danford and Huber’s population and the current population sample may be a result of any number of reasons including improved nutrition and medical care over the last 17 years.

6.1.1 Pica

10% of the sample population exhibited pica at least some of the time. This rate was similar to that found by other studies of pica in this population (McAlphine and Singh, 1986, Tewari et al, 1995). Furthermore, results seemed to support the hypothesis (H2a) that pica is more frequently exhibited by those with autism. Only 2 out of the 40 residents with autism, were also identified as having a psychotic disorder and there was no association found between pica and psychosis. This appeared to dispute the hypothesis (H2b), that there is an association between Pica and mental illness, and therefore failed to lend evidence to Kinnell’s (1985) speculation that Pica is a symptom of psychotic tendencies. Results also failed to support previous studies (McAlpine and Singh, 1986, Tewari et al, 1995) which showed a higher prevalence of pica in those with severe as opposed to mild learning disabilities (disputing hypothesis H2c).

The current study did not find a link between pica and iron deficient anaemia (disputing H2d). However, there were only 5 residents in the sample population identified as being anaemic, and two of those were also taking iron supplements. Additionally, there was no measure of anaemia in the current study, only reports of its existence. These reports may not have been accurate.

Pica was found to decrease with age (supporting hypothesis H2e) which seemed to support similar results found by Danford and Huber (1981) and McAlphine and Singh (1986). Results were also similar to Danford and Huber in that pica was observed more in those with increasing behavioural problems and those on medication.

In the current study, females on contraceptive medication seemed to exhibit more pica compared to those not taking contraceptive. Oral contraceptives are found to increase iron levels in the body (Rivera et al 1983; Masse and Roberge, 1992) and have little
effect on the body's zinc levels (Liukko et al., 1988). Therefore the link between oral contraceptives and pica cannot readily be explained by iron or zinc deficiency. There may be other chemical determinants for pica, which are as yet unknown and which have a link to contraception. Further research is needed to explore this.

6.1.2 Reluctance to Eat

Within the current study residents who were more reluctant to eat were found more likely to be of lower weight, and be on a weight gain diet. Female residents showed more reluctance to eat than male residents, and those over the age of 71 showed greatest reluctance to eat compared to younger residents. There are a number of possible reasons why a high percentage of residents were found to exhibit reluctance to eat on a regular basis. These include: the possible existence of eating disorders like anorexia and/or bulimia; physical causes for loss of appetite and quality of hospital food.

6.1.2.1 Dieting behaviour and/or eating disorder

Reluctance to eat could be a behavioural indicator of an underlying eating disorder such as (or similar to) anorexia or bulimia nervosa, of which a restricted food intake is one of a number of features. The finding that females seemed to be more reluctant to eat compared to males could also support this idea, as eating disorders are more prevalent in females in the general population (Hoek, 1991). However, in addition to restricted intake of food, a diagnosis of anorexia or bulimia nervosa, according to DSM-IV or ICD-10 requires a disturbance or distortion of body image. Only a small minority of the sample population exhibited concerns about their bodies and there was no association between reluctance to eat and concerns about body image. This could therefore suggest that reluctance to eat was not a strong indicator for an underlying eating disorder, in the majority of the population.

Residents with mental health problems in this population, appeared more reluctant to eat and more concerned about their body image, compared to residents with no mental health difficulties (supporting hypothesis H5). This could indicate underlying
anorexia or bulimia nervosa for these residents, particular as both these disorders are found to co-exist with other psychiatric illnesses. (e.g.: Hugo and Lacey, 1998; Deckelman et al, 1997). Residents’ reluctance to eat however, could equally be a result of a loss of appetite (as opposed to anorexia or bulimia), as found in those who suffer from an affective disorders such as depression (e.g.: Kazes et al, 1993, 1994). With this type of study, it is very difficult to conclude whether residents who have a mental illness are more reluctant to eat because of a) their primary illness, or b) the possible co-existence of an underlying eating disorder or c) the influence of another confounding variable such as medication effects.

6.1.2.2 Physical Causes for Loss of Appetite

In the current study, residents who experienced an acute physical illness within the previous 6 months of the survey showed a significantly greater reluctance to eat (supporting H6). However, because there was no measurement of residents eating patterns prior to their physical illnesses, the author can only speculate that physical illness affects appetite and eating patterns for people with learning disabilities.

The small but significant correlation between reluctance to eat and a) difficulties with eating and b) visual ability, might suggest that residents who have problems with choking, regurgitation and swallowing or had difficulties seeing their food, were more reluctant to eat it, compared to residents without such difficulties. Danford and Huber (1981) found a similar association between visual impairment and anorexia (reluctance to eat) in their population survey.

6.1.2.3 Quality of Food

The small but significant correlation between residents’ reluctance to eat and preoccupation with food might suggest that some of the sample population were reluctant to eat but still retained an appetite for and interest in food. The food that residents received in the hospital was known as “cooked chill”. This food was cooked, chilled and delivered by an independent outside caterer, and then heated up on the hospital site for residents to eat. A number of staff members including dieticians, reported that the hospital food was of poor standard and lacking in taste.
Reluctance to eat could therefore be due in part to residents' dislike of the hospital food.

6.1.3 Preoccupation with Food

Those between the age of 31-40, or residents with greater body mass exhibited preoccupation for food with the most frequency. Residents who had better cognitive and physical abilities (better vision, mobility, hand control and ability to self-feed) seemed more preoccupied with food than residents with greater disabilities. It cannot be assumed from this result, that those with greater disabilities do not experience a preoccupation with food. They may simply be more restricted in their ability to express it, either behaviourally and/or verbally.

Preoccupation with food in this population could indicate that residents are hungry, despite receiving three meals a day. Hunger could also prevail for those residents who dislike and are reluctance to eat the hospital food. Other possible reasons for the existence of this eating pattern are discussed below.

6.1.3.1 Preoccupation for Food as a Form of Challenging Behaviour

Residents with increasing severity of behavioural problems seemed more preoccupied with food. There are a number of reasons why people with learning disabilities exhibit behavioural problems, including gaining social interaction, gaining access to positive and enjoyable environments, escape from adverse situations, reacting to emotional distress, or frustration with not being able to communicate needs. Being preoccupied with food (asking for food, taking food, indicating hunger) may be a means of communicating with staff and gaining staff attention.

Another explanation for the finding is the possibility that the severity and frequency of residents' preoccupation for food, was viewed by hospital staff as a severe behavioural problem. Therefore for some residents, the definition of behavioural problems, as measured by the study questionnaire could have been the eating pattern itself. As a way of helping to distinguish those residents who had other challenging
behaviours, (apart from ones involving food) it would have been useful to measure the *types* of behavioural problems that residents exhibited, as opposed to just rating the severity.

6.1.3.2 *Using Food to Enhance Mood*

Eating can be a very enjoyable activity and may be one of only a few enjoyable pastimes for those living in restricted environments such as hospitals. Food can be a way of enriching a person's life and enhancing mood particularly at times of distress (Townsley and Robinson, 1997). The process of "comfort eating" may be the underlying reason why preoccupation with food appeared greater for residents with mental health problems. In research on normal adult populations, food cravings have been associated with certain mental health difficulties, particularly affective disorders such as depression (e.g.: Fernstrom et al, 1987; Kazes et al 1994). In their study, O'Brien and Whitehouse (1990) found that a group of people with learning disabilities and depression showed excessive eating, choosing sweet foods and searching for food, compared to those with no psychiatric diagnosis. Surprisingly, in the current study, preoccupation for food was not significantly greater for residents with affective disorders than for those with any other psychiatric diagnosis. However the number of residents with a diagnosis of depression was small.

6.1.3.3 *Drug Effects on Appetite*

Residents on psychotropic drugs were found to exhibit greater preoccupation for food. This seems to support past research showing that certain neuroleptic and antidepressant drugs have varying abilities to increase appetite and stimulate carbohydrate craving. (Bernstein, 1987). However, those residents on psychotropic medication, were also the same residents who exhibited mental health problems and/or behavioural difficulties. All these variables were found to be associated with preoccupation for food. It is therefore difficult to separate the *individual* effects of each of these factors. A further study is needed to explore this in greater depth, while controlling for each confounding variable.
Females on contraceptive medication seemed to have a greater preoccupation with food (and greater frequency of pica) compared to females who were not on contraceptive medication. Further research is needed to explore the influence of contraception (or hormone treatment) on the eating patterns of people with learning disabilities.

### 6.1.4 Concerns about Body Image

Despite being the least prevalent pattern found in the sample population, 7% of residents did exhibit some concerns about body image. It is therefore, feasible that for some individual residents this could represent a risk factor or symptom of anorexia or bulimia nervosa. Female residents appeared to exhibit greater concerns about body image than males and this is comparable to other studies (Wardle and Beales, 1986, Brodie et al, 1991, Cullari, et al 1998) of gender differences in body image, in normal adult and adolescent populations (supporting hypothesis \(H4\)).

Residents with greater concerns for body image, appeared more likely to be preoccupied with food, be more overweight and be on weight loss diets. Concerns for body image, as measured in this study, did not necessarily indicate that residents had a *distorted* image of themselves or that their concerns indicated that they might have an eating disorder. “Concern for Body Image” may have represented a realistic and normal awareness of weight and shape.

As for other populations, what seems important for identifying *distorted* body image (as opposed to normal/healthy concern), is taking other factors into account such as a) reluctance to eat, b) weight loss and c) bingeing behaviour. These behaviours may be expressed only by individuals who have freedom and control over their environment, particularly regarding access to food, choices of food and ability to self-feed. These individuals are more likely to be mildly to moderately disabled (see next section) and have more capacity for independent living.
6.1.4.1 Body Image and Cognitive Ability

One of the most important and interesting findings from this study, was the association between body image and level of learning disability. Residents with higher levels of cognitive ability appeared to exhibit greater concerns or awareness with regards to their body image.

Unlike the other eating patterns measured in this study, concern for body image is defined cognitively and verbally as opposed to being measured in behavioural terms. To express concerns about body image, residents are required to talk about their weight and dieting and express thoughts about being overweight. Those with severe and profound learning disabilities may have concerns about their bodies, but lack the ability to express them as strongly or as frequently as those with greater verbal abilities.

6.1.4.2 Identifying Anorexia And Bulimia Nervosa in PLD

The issue of communication extends to diagnosing anorexia and bulimia nervosa in PLD. As stated in the literature review, there have been a number of case studies of anorexia nervosa in people with severe learning disabilities. However on reading these, it is apparent that diagnosis of anorexia or bulimia has relied on the person being able to express themselves verbally, as well as having the freedom and ability to choose or avoid food, lose weight, induce vomiting etc. Diagnosis of eating disorders in PLD has relied on diagnostic criteria, developed from research on normal populations. There is a need to develop appropriate diagnostic criteria and special measurement tools, which can be used to detect body image disturbance and eating disorders in PLD.

Questionnaires and inventories for measuring body image disturbance and eating disorders in children have already been developed or adapted from tools developed for use with adolescents and adults. These have used simplified language and perceptual ways of measuring symptoms. For example, instruments for measuring body image disturbances have focussed on the use of figural stimuli (e.g.: silhouettes, line drawings of children). Respondents are required to make a choice with regards to
their perceived current and ideal body shape (e.g.: Vernon Guidry and Williamson, 1996; Collins, 1991; Dowdney et al 1995). These pictorial measures of body image have been found to distinguish those with eating disturbance from normal control and have the advantage of requiring limited verbal responding. However, they still require receptive language skills for understanding the aims of the task and concepts such as ideal shape, size etc.

6.1.5 *Difficulties with Eating*

Residents with greater severity of learning disability, needing more staff input and assistance with eating, appeared to exhibit greater difficulties with swallowing, chewing and regurgitating food. Difficulties with eating appeared not be associated with visual impairments, mobility problems or poor hand control, thus disputing the hypothesis (*H3*) that there will be an association between level of physical ability and eating difficulties such as swallowing and rumination. The ability to *self-feed* was found to be associated with vision, mobility and hand control and may therefore indicate difficulties with manipulating cutlery and getting food from plate into mouth. Disabilities of vision, mobility and hand control would not necessarily affect resident’s ability to chew or swallow food. Surprisingly, residents on soft diets did not seem to have greater problems with chewing, swallowing and regurgitation. This could indicate that soft diets were a successful intervention for reducing these difficulties in this population.

Residents, who had difficulties with eating, seemed also to be generally more reluctant to eat. It is difficult to be conclusive as to the reason for this association. It could be argued that if an individual is having difficulties with mastication and ingestion, they would most probably find eating very unpleasurable and therefore might be more reluctant to eat. Alternatively, individuals who are reluctant to eat for other reasons, (such as a fear of getting fat or a dislike of the food) may chew for long periods of time, avoid swallowing and regurgitate their food. For both these reasons, weight loss could be apparent and the need for a weight gain diet identified. Due to the correlational nature of this study, it cannot be established whether difficulties with
eating is primary or secondary to reluctance to eat for the majority of the sample population. For any individual resident scoring highly on this scale of the PEQ, further assessment by a speech and language therapist would be useful in identifying or ruling out physical problems like dysphagia, which can greatly affect nutrition and eating (e.g. Kennedy et al 1997).

6.2 METHODOLOGICAL CRITIQUE

6.2.1 Reliability of the PEQ

The Patterns of Eating Questionnaire (PEQ), had good inter-rater and inter-item reliability. It differentiated between groups within the sample population and gave sensible patterns of eating. Testing for and establishing test-retest reliability would further strengthen the instrument.

6.2.2 Validity of the PEQ

In the current study, the content validity of each factor extracted using the principal components factor analysis, was established. Further research is needed to establish the validity of the factor labels/descriptions, as these were devised by the author prior to content validity procedures.

In the current study, the PEQ also lacks construct validity i.e.: the degree to which eating patterns measured by the PEQ correlate with other measures or observations of eating patterns in the study population. It was beyond the scope and aims of this study to develop further validity checks on the PEQ other than the ones carried out. To obtain construct validity for the PEQ, an independent rating of eating patterns (through observation), for a selection of the population, could be correlated with nurse ratings of eating patterns on the PEQ.

6.2.3 Correlational Nature of the Study

The current study is a correlational study. Relationships between eating patterns and population characteristics were established but care needs to be taken in inferring causality between variables because of the possible effects of uncontrolled,
confounding variables. Indeed, some of the population characteristics measured within this study were correlated with each other (e.g. residents levels of ability). It would be necessary to use parametric statistics (such as partial correlations and multiple regression) in order to control for the effects of these potentially confounding variables when measuring for an association between one specific population characteristic and an eating pattern.

In this study, associations between variables need careful interpretation, and future research should aim to control for confounding variables by using experimental (as opposed to correlational) methodology. Only in this way, can the etiology of eating patterns be established in this population, and preventative interventions developed.

6.3 FUTURE RESEARCH

From this study, a number of future research projects are indicated;

1. With further validity and reliability checks, the PEQ could be used as a screening tool for measuring problematic eating patterns and a tool for helping to evaluate the effectiveness of clinical interventions aimed at treating eating difficulties.

2. Further research is needed to help develop appropriate diagnostic criteria for eating disorders within this population. The development and validation of instruments measuring body image would greatly contribute to this.

3. A follow up study, using more in-depth semi-structured face to face interviews with residents themselves might help to determine whether or not an eating disorder like anorexia and bulimia can be diagnosed. These face to face interview schedules would need to be developed for this population, using appropriate diagnostic criteria.

4. A number of smaller, experimental research projects are needed to explore causal relationships between population characteristics and eating patterns.

6.4 CONCLUSION

This study demonstrates that eating problems are likely to occur frequently in institutionalised populations with learning disabilities. The prevalence of pica in the
current study was comparable to other studies of pica in this population. It has also been demonstrated that adults with learning disabilities do seem to be able to express concerns about body image and this appears to be most prevalent in those with higher levels of cognitive ability. It is not clear whether those with severe and profound disabilities have an undeveloped sense of body image or are unable to express concerns about body image in ways which are easily observable and measurable. Further in-depth assessment using semi-structured interviews, of those residents with body image concerns, might further help to identify those who have an eating disorder such as anorexia or bulimia nervosa.

There were a number of statistical associations found between eating patterns and population characteristics. In particular, those with mental health problems seemed to exhibit greater difficulties with eating. Eating patterns also appeared to relate to demographic factors (age and sex), level of disability, (cognitive and physical), medication, physical illness, autism, and behavioural difficulties. Eating patterns also seemed to be associated with weight and changes in weight and diets. It was not possible to ascertain cause and effect relationships between the population characteristics and eating behaviours, although causal hypotheses were discussed. Further research is necessary to a) establish reliable and valid diagnostic criteria and measuring tools for eating patterns in this population, b) establish the etiological nature of these patterns and c) develop treatment and prevention strategies for these eating disturbances.
7 REFERENCES


Harris, B., Young, J. and Hughes, B. Comparative effects of seven antidepressant regimes on appetite, weight and carbohydrate preference. *British Journal of Psychiatry, 148*, 590-592.


APPENDIX I:

THE PATTERNS OF EATING QUESTIONNAIRE
SECTION 1: RESIDENT DEMOGRAPHICS

1. Name of Resident: ............................................................................................................................................

2. Please state your relationship to the resident: (please tick)
   a) Keyworker  
   b) Home Manager  
   c) Care Co-ordinator  
   d) Other  
   (Please state your relationship ..........................................................)

3. How long have you known the resident: (months, years) ........................................................................

4. Age of Resident: .......................

5. Sex: Female / Male

6. Height of Resident: .......................

7. Residents most recently recorded weight: .......................

8. Name of Home/Residency: ..............................................................................................................................

9. Is the resident on medication:
   (e.g.: Anticonvulsant, Antipsychotic, Antidepressant)  Yes / No / Don’t know
   If Yes, please name:...........................................................................................................................................

10. Does the resident have a diagnosed Mental Health Problem:  Yes / No / Don’t Know
    If Yes, please name:...........................................................................................................................................

11. Does the resident have a Developmental Disorder or Diagnosed Syndrome
    (e.g. Downs Syndrome, Cerebral Palsy, Cri du Chat, Autism, Aspergers):  Yes / No / Don’t Know
    If Yes, please list each one:..........................................................................................................................

12. Does the resident have behavioural problems: (please tick)
    a) No problems  
    b) Mild/moderate problems (occasional staff supervision)  
    c) Severe problems (staff must often intervene/supervise)  

13. Does the resident have any medical problems
    (eg: diabetes, epilepsy, etc)  Yes / No / Don’t Know
    If Yes, please name:...........................................................................................................................................

14. Has the resident had any bodily illness over the last 6 months  Yes / No / Don’t Know
    which could have resulted in either weight loss and weight gain:
    If Yes, please name:...........................................................................................................................................

15. What is the condition of the residents teeth: (Please tick)
    a) Own teeth - good  
    b) Own Teeth - bad  
    c) Dentures  
    d) No teeth  

FOR FEMALE RESIDENTS ONLY

16. Please state the current pattern of the residents periods: (please tick)
   a) No periods  
   b) Irregular periods  
   c) Regular periods  
   d) Menopausal  

17. Is the resident taking the contraceptive pill/receiving contraceptive depot injections:
   Yes / No / Don’t know

SECTION 2: LEVEL OF ABILITIES

1. Most Used Level of Communication: (please tick)
   a) No spoken language  
   b) Signing  
   c) Echoes/repeats what others say  
   d) One word  
   e) Two-three words  
   f) Full sentences  

2. Level of Understanding/Receptive Language: (please tick)
   a) Little or no understanding of speech/signing  
   b) Gestures/signing/symbols only  
   c) Single commands  
   d) Sequence of two commands  
   e) Range of Instructions  

3. Level of Supervision Needed: (please tick)
   a) One to one  
   b) Some extra help  
   c) Normal staff input  

4. Level of Mobility: (please tick)
   a) Non-mobile - needs wheelchair  
   b) Needs help walking or with stairs  
   c) Walks unaided  

5. Hand Control Problems: (please tick)
   a) No problems  
   b) Mild/moderate (slight tremor)  
   c) Severe (needs help getting food to mouth)  

6. Level of Visual Impairment: (please tick)
   a) No visual impairment/fine when using glasses  
   b) Limited sight (even with glasses)  
   c) Severe visual impairment  

7. Level of Learning Disability: (please tick)
   a) Profound  
   b) Severe  
   c) Moderate  
   d) Mild  

SECTION 3: FEEDING, DIETS AND WEIGHT

A) Is the resident able to feed himself/herself: (please tick)
   a) Able to feed self  [ ]  b) Assisted feeding  [ ]  c) Gastric tube feeding  [ ]

B) Has the resident been on any special diets within the last 3 MONTHS:
   Y / N / Don't Know  If yes, please name (eg: weight gain/loss, vegetarian etc)..............................

C) How much? (please circle the number which best describes the resident)

<table>
<thead>
<tr>
<th>Not at all</th>
<th>Very Slightly</th>
<th>Mildly</th>
<th>Moderately</th>
<th>Severely</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

1) Is the resident overweight for his/her age and height
   1  2  3  4  5

2) Is the resident underweight for his/her age and height
   1  2  3  4  5

3) Has the resident lost weight over the last 6 months
   1  2  3  4  5

4) Has the resident gained weight over the last 6 months
   1  2  3  4  5
### SECTION 4: EATING PATTERNS

How often has the resident done the following in the last 3 MONTHS? *(please circle the number which best describes the resident)*

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Seldom</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
<th>Beh’ requires special restrictions/programme</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
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<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>N/A</td>
<td>resident unable to feed self</td>
</tr>
</tbody>
</table>

1) Avoids eating sweet and/or fatty foods
   1 2 3 4 5 6 N/A

2) Chooses only to eat sweet and/or fatty foods
   1 2 3 4 5 6 N/A

3) Eats a limited variety of foods
   1 2 3 4 5 6 N/A

4) Eats inappropriate (i.e.: frozen or uncooked) foods
   1 2 3 4 5 6 N/A

5) Eats inedible (non-food) objects. *(dirt, rubbish etc: Please specify)*
   1 2 3 4 5 6 N/A

6) Takes longer than others to eat a meal
   1 2 3 4 5 6 N/A

7) Eats a meal more quickly than others
   1 2 3 4 5 6 N/A

8) Refuses to eat his/her meal
   1 2 3 4 5 6 N/A

9) Needs encouragement to eat and/or finish a meal
   1 2 3 4 5 6 N/A

10) Doesn’t finish his/her meal
    1 2 3 4 5 6 N/A

11) Eats very little
    1 2 3 4 5 6 N/A

12) Eats more food than others *(asks/receives second helpings/double portions)*
    1 2 3 4 5 6 N/A

13) Drinks to excess *(coffee, tea, alcohol, water etc: Please specify)*
    1 2 3 4 5 6 N/A
CONT: How often has the resident done the following in the last 3 MONTHS? (please circle the number which best describes the resident)

<table>
<thead>
<tr>
<th>Never</th>
<th>Seldom</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
<th>Beh’ requires special restrictions/programme</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>N/A</td>
</tr>
</tbody>
</table>

14) Requests food between mealtimes  
1 2 3 4 5 6 N/A

15) Chokes on food  
1 2 3 4 5 6 N/A

16) Lets food sit in his/her mouth  
1 2 3 4 5 6 N/A

17) Chews food for long periods of time  
1 2 3 4 5 6 N/A

18) Regurgitates their food  
1 2 3 4 5 6 N/A

19) Searches for food between mealtimes  
1 2 3 4 5 6 N/A

20) Hides food  
1 2 3 4 5 6 N/A

21) Takes food (eg: from kitchens, shops, other residents)  
1 2 3 4 5 6 N/A

22) Chooses only to eat certain coloured and/or textured foods  
1 2 3 4 5 6 N/A

23) Complains of being hungry or indicates hunger  
1 2 3 4 5 6 N/A

24) Eats large amounts of food within a short period of time outside of mealtimes (binge)  
1 2 3 4 5 6 N/A

25) Appears anxious at mealtimes  
1 2 3 4 5 6 N/A

26) Dislikes eating  
1 2 3 4 5 6 N/A

27) Talks about his/her weight  
1 2 3 4 5 6 N/A
CONT: How often has the resident done the following in the last 3 MONTHS? (please circle the number which best describes the resident)

<table>
<thead>
<tr>
<th>Never</th>
<th>Seldom</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
<th>Beh’ requires special restrictions/programme</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>N/A</td>
</tr>
</tbody>
</table>

- resident unable to feed self

28) Thinks they are fat
   1 2 3 4 5 6 N/A

29) Talks about dieting/losing weight
   1 2 3 4 5 6 N/A

30) Weighs him/herself or requests to be weighed
   1 2 3 4 5 6 N/A

31) Vomits after eating (self induced / medical reasons / Don’t know: Please delete as applicable)
   1 2 3 4 5 6 N/A

32) Chooses to takes strenuous physical exercise
   1 2 3 4 5 6 N/A

Any other comments about the residents eating patterns:

.................................................................................................................................
.................................................................................................................................
.................................................................................................................................
.................................................................................................................................

THANK YOU FOR YOUR CO-OPERATION
APPENDIX II

COHEN KAPPA STATISTICS CALCULATED USING MICROSOFT EXCEL
FORMULA FOR COHEN'S KAPPA

Kappa =

\[
\frac{(\text{Total Number of Ratings} \times \text{Total Number of Agreements}) - (\text{Sum (Row Totals x Column Totals)})}{(\text{Total number of Ratings})^2 - (\text{Sum (Row Totals x Column Totals)})}
\]

Agreement Between Experts 1 and 2

<table>
<thead>
<tr>
<th></th>
<th>F 1</th>
<th>F 2</th>
<th>F 3</th>
<th>F 4</th>
<th>F 5</th>
<th>Pica</th>
<th>Other</th>
<th>Totals</th>
</tr>
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<tbody>
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Total Number of Ratings = 28. Total Agreement = 19. Sum of Rows x Columns = 121

Kappa = 0.61991

Agreement Between Experts 1 and 3

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Total Number of Ratings = 28. Total Agreement = 18. Sum of Rows x Columns = 125

Kappa = 0.575114
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Total Number of Ratings – 28. Total Agreement = 19. Sum of RowsxColumns = 111

Kappa = 0.625557

### Agreement Between Experts 2 and 3

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Kappa = 0.691824

### Agreement Between Experts 2 and 4

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Total Number of Ratings – 28. Total Agreement = 21. Sum of RowsxColumns = 128
Kappa = 0.70122

**Agreement Between Experts 3 and 4**

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Total Number of Ratings = 28. Total Agreement = 20. Sum of RowsxColumns = 133

Kappa = 0.655914

**Average Level of Agreement**

Average Cohen Kappa = Sum of Kappa's / 6 = 0.644923