An Investigation of Long-term Memory and Executive Functioning in Adults with Downs Syndrome

by

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VOLUME I

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**Introduction to the Portfolio**

This portfolio contains work completed over the three years of the course. The academic dossier consists of four essays covering the four core placements. The clinical dossier contains a summary of the details of all the placements and a summary of each of the five case reports. The complete case reports are in a separate confidential clinical volume with the five placement contracts, clinical activity logbooks and placement evaluation forms. The research dossier consists of a logbook of research experience, a service related research project and a major research project.

The work in each chapter is presented in the order it was completed in order to show the developmental nature of the course.
Adult Mental Health Essay

Compare and Contrast Cognitive Behavioural and Psychoanalytic Concepts of Depression in Adults, and the Evidence Underlying Each of These Models

Completed in Year 1
Introduction

Depression as a normal mood state is common. It is also a common mental health problem encountered in clinical practice. Clinical depression has a lifetime risk of 12% for males and 20% for females and at any one time about 5% of the population is suffering from it (Sturt, Kumarkura & Der, 1984). Clinical depression presents itself differently in each individual. However, a number of common themes have been identified. The Diagnostic and Statistical Manual, Fourth Edition (DSM-IV; American Psychiatric Association, 1994), defines depression according to a number of criteria, including both physiological and psychological symptoms.

The prevalence of depression in the population, combined with the existence of psychological symptoms in its presentation, means it has always been an area of interest to psychologists. From early work by Freud (e.g. Freud, 1917) through to recent times (e.g. Mazura, Bruce, Maciejewski & Jacobs, 2000), there has been study and debate about the psychological processes involved in depression. A variety of psychological models and treatment approaches to depression have thus been developed. The concepts of depression behind two of these models – the cognitive behavioural and psychoanalytic - and the evidence for them will be discussed in this essay.

Firstly, cognitive behavioural concepts of depression will be outlined and some evidence for them reviewed. It will then be acknowledged that the label “psychoanalytic” covers a numerous and varied selection of approaches, which cannot all be covered in this essay. Therefore, a specific approach to depression, which is based on psychoanalytic concepts, will be outlined and the evidence for some of the concepts behind it reviewed. Similarities and differences between cognitive behavioural and psychoanalytic approaches, and the evidence for them, will then be discussed. In conclusion, some implications this has for future practice and research in the field of depression will be outlined.

Cognitive Behavioural Concepts of Depression

The development of cognitive theories (e.g. Ellis, 1962; Beck, 1967) followed from the poor outcomes of behavioural approaches to depression and a move towards cognitive theories in psychology as a whole (Rachman, 1997, gives an outline of the development of behavioural, cognitive and cognitive-behavioural therapies). Most cognitive therapies incorporated some behavioural tasks and the behavioural notion of measuring outcomes. Thus, a continuum
between purely behavioural and purely cognitive approaches developed, with cognitive-behavioural concepts broadly defined as anything between these two extremes.

Cognitive behavioural therapy is a widely used treatment for clinical depression (Fennell, 1989). Its main goal is to help people bring about desired change in their lives. A collaborative relationship is encouraged, in which the patient feels safe to disclose important information. The therapist and patient work together to formulate reasons for the depression continuing and then test them out through behavioural experiments. The therapy focuses on the symptoms of depression which are causing problems in the here and now. Negative automatic thoughts are identified and challenged. This is achieved through the development of skills that enable these thoughts to be perceived. The evidence for the thoughts can then be examined and logical errors in them identified. Thus, the therapy looks for opportunities for new adaptive learning and aims to produce changes outside the clinical setting.

That gives a brief overview of cognitive behavioural therapy. However, what are the cognitive-behavioural concepts of depression that lie behind the therapy?

Cognitive behavioural concepts of depression centre upon the notion that our actions are based upon how we perceive events to be. Thus our emotional and behavioural responses to events are firmly linked with our thoughts. When we are depressed, we produce thoughts that are negative (in that they evaluate outcomes of events poorly) and automatic (in that they “pop in” to the mind involuntarily and may be unconscious). Beck identified a “negative triad” of these negative automatic thoughts (e.g. Beck, 1967), which he argued formed the basis of depressive thinking. This triad consists of thoughts about the self, current functioning and the future. The thoughts contain a number of systematical logical errors (e.g. generalisation, personalisation; see Fennell (1989) for a fuller guide), caused through a negatively biased view of the world. These negative thoughts lower our mood. This lower mood leads us in to patterns of behaviour that reinforce the negative triad of thoughts and prevent us from having experiences with which we can challenge them. Thus the negative thoughts continue and our mood worsens. A reciprocal relationship between thoughts and moods is started, which results in a “spiral” into deeper states of depression.

Negative automatic thoughts are therefore a key component in cognitive behavioural concepts of how depression is maintained. Cognitive factors are also thought to play a role in the development of depression.
Cognitive behavioural theory suggests we use cognitive structures called “schemata” to organise our thoughts (e.g. Beck, 1967). These are theories or rules we develop about how our world should be, which enable us to respond to challenges we meet in our day-to-day lives. However, some schemata have the potential to impair our functioning. These are called dysfunctional beliefs and often concern what we believe is important for us to be a happy and worthwhile person. The difficulties in our functioning are triggered by a “critical incident”. This produces responses in our environment or us that do not fit with the dysfunctional belief. We therefore evaluate ourselves negatively, which begins the production of negative automatic thoughts.

Cognitive behavioural theorists have also proposed that certain personality dimensions may make us particularly vulnerable to certain critical incidents. The dimensions most commonly proposed are sociotropy and autonomy (e.g. Beck, 1983). Individuals with the factor of sociotropy are thought to be very focussed on interpersonal relationships with others. Thus, they are particularly at risk of developing depression following critical incidents involving rejection, loss or other interpersonal conflict. Individuals with the factor of autonomy rate self-identity and personal achievement as very important. They are therefore at particular risk of developing depression following incidents when they perceive they have performed poorly or not attained some personal goal.

To summarise, the cognitive behavioural concept of depression links our mood, behaviour and thoughts. A stress-vulnerability model is proposed. We develop dysfunctional beliefs (the vulnerability), which do not interfere with our mood or thoughts until they are activated by a critical incident (the stressor). Personality dimensions, such as sociotropy and autonomy, make us particularly vulnerable to certain critical incidents. Once activated, dysfunctional beliefs lead us to evaluate ourselves, our current functioning and our future in a negative fashion (the negative triad). These thoughts form a reciprocal relationship with our mood state, creating a vicious circle that worsens or maintains the depressive episode.

Evidence for Cognitive Behavioural Concepts of Depression

Cognitive behaviour therapy for depression and some of the concepts behind it have been outlined. These concepts included negative automatic thoughts, dysfunctional beliefs and the personality dimensions of sociotropy and autonomy. But what evidence exists to support the existence of these concepts?
In their extensive review on the empirical status of the cognitive theory of depression, Haaga and colleagues (Haaga, Dyck & Ernst, 1991) looked at the research on negative thoughts in depression. They reported a number of studies that had found depressed people have more negative thoughts than non-depressed people. Other studies had also found the same people reported more negative thoughts during a depressive episode than when they had recovered. Stader and Hokansson (1998) compared daily symptoms of depression with dependency feelings, negative thoughts and interpersonal stress in a non-clinical student population. They found that when students reported higher levels of depressive symptoms, they also reported higher levels of all the other ratings. Thus, an increase in depressive symptoms was associated with an increase in negative thoughts. Further, although there were increased ratings of dependency feelings and interpersonal stress on the day prior to increased depressive symptoms, there was no increase in negative thoughts. Thus negative thoughts were strongly associated with the depressed period itself and not precursors.

Haaga and colleagues (1991) also reviewed the evidence for the “causal” concepts in cognitive theory, including dysfunctional beliefs. They argued that these beliefs should be stable over time and not dependent upon mood state. They found inconclusive evidence for dysfunctional beliefs based on this premise. However, they later questioned the stability of these beliefs, and thus this method of verifying their existence. Another study looked at dysfunctional attitudes and depressive symptoms in a non-clinical population before and after their mid-term exams (Joiner, Metalsky, Lew & Klocek, 1999). It was found that students high in dysfunctional attitudes experienced increases in depressive symptoms, but only if they achieved a low exam grade score. Students high in dysfunctional attitudes who achieved high grades and students low in dysfunctional attitudes did not experience an increase in depressive symptoms. A further result was that specifically depressive cognitions (rather than anxious cognitions) contributed to the development of symptoms. This suggests depressive thoughts are specifically linked to depressive symptoms and not other areas of psychopathology. Therefore, there is some evidence to support the concept of dysfunctional beliefs. However, the nature of these beliefs is unclear (Haaga, Dyck & Ernst, 1991), so the evidence is also.

The concepts of sociotropy and autonomy have been the subject of considerable debate. One review (Haaga, Dyck & Ernst, 1991) concluded that the studies to date had been limited and inconclusive. Coyne and Whiffen (1995) reported that although there was some supporting evidence that a sociotropic personality dimension and a congruent stressor led to the development of depression, this was far from conclusive. They then proposed that the sociotropy and autonomy dimensions are in fact restrictive and unhelpful in concepts of
depression and that it may be better to dismiss them altogether. This appears to be supported
by the research of Mazura and colleagues (Mazura, Bruce, Maciejewski, & Jacobs, 2000).
They could find no link between a cognitive personality style (sociotropy or autonomy) and
congruent stressor (interpersonal events or achievement events) that led to depression.
However, others have broadened the search for cognitive vulnerability types and discussed the
possibility of others (e.g. Abramson, Alloy & Hogan, 1997). Therefore, the current empirical
data on the dimensions of sociotropy and autonomy remains inconclusive, although research
in this area continues to grow (Alloy, 1997).

A further way of providing support for cognitive behavioural concepts of depression may be
to look at research that shows the effectiveness of treatments based on those concepts. One
study in this area (Hollon et al., 1992) compared treatment groups who received cognitive
behavioural therapy with clinical management, an anti-depressant with clinical management
and cognitive behavioural therapy alone. They concluded that all groups showed equal
efficacy at the end of treatment.

In conclusion, a substantial review of the literature in 1991 (Haaga, Dyck & Ernst, 1991)
found strong evidence for the existence of negative cognitions in depressive episodes. This
has since been supported by further studies (e.g. Stoka & Hokanson, 1998). There is also
evidence that these cognitions are specific to depressive symptoms (e.g. Joiner Jr., Metalsky,
Lew & Klocek, 1999), which supports the idea of a specific cognitive aetiology in depression.
Research findings on dysfunctional beliefs also show some supporting evidence (Joiner Jr.,
Metalsky, Lew & Klocek, 1999), but there appears to be some uncertainty about the
boundaries between dysfunctional beliefs and negative thoughts (Haaga, Dyck & Ernst,
1991). Evidence for the sociotropic and autonomic personality dimensions remains
inconclusive, with ongoing debate over whether they are useful or valid constructs (e.g.
Coyne & Whiffen, 1995; Abramson, Alloy & Hogan, 1997). Outcome studies of cognitive
behavioural therapy have demonstrated it to be comparable to anti-depressant medication in
its effectiveness at treating depression (e.g. Hollon et al., 1992), which also gives support to
the concepts behind the treatment.

**Psychoanalytic Concepts of Depression**

The psychoanalytic movement began with the work of Freud (e.g. Freud, 1917). From this
start it has expanded and diversified, with numerous other psychoanalytic (or psychodynamic)
concepts and psychotherapies being developed (e.g. Klein, 1932; Bowlby, 1969; Malan, 1979).

A consistent psychoanalytical concept in depression is the notion of loss. Freud (1917) saw some comparisons between melancholia (now called depression) and the mourning process. However, loss in depression does not have to be physical, as in the case of bereavement. It can be any loss that affects our self-esteem (e.g. rejection by another person). Our emotional reaction to loss is to feel sadness about the lost object. However, psychoanalysis proposes that we are motivated by instinctive drives (e.g. the attachment drive of Bowlby (1969)), which manifest themselves in the form of conscious wishes. As well as reacting with sadness towards the lost object, we are also instinctively driven to feel anger towards it for making us feel such emotional pain. To avoid this conflict of emotions in the conscious mind we use "defence mechanisms" (e.g. denial, repression). These remove the anger to the unconscious level, where it gets turned against the self. This anger against the self manifests itself in the conscious world through the symptoms of depression.

This outlines one conceptualisation of depression using general psychoanalytic concepts. Our emotional responses are placed at the core of our functioning. The role of the therapist is to help clients gain insight about their current difficulties by relating them to unconscious processes that have resulted from conflicts in early relationships. The symptoms of depression are the result of an emotional response to these unconscious conflicts. Thus therapy aims to alter fundamental personality difficulties.

Although this gives a brief outline of some general psychoanalytic concepts of depression, it is by no means exhaustive. The diversity of the psychoanalytic movement prevents all of the concepts being discussed in this essay. So, which psychoanalytic approach should be outlined, considering that the evidence for the concepts behind the approach will be analysed as well?

In their book on contemporary psychoanalysis, Bateman and Holmes (1995) acknowledge that although there has always been an awareness of the need for research in the field of long-term psychoanalysis, little has been carried out that would be acceptable by today's standards (e.g. methodologically poor case studies). They suggest a number of reasons for this, including the difficulty in quantifying the outcomes which psychoanalysis hopes to produce and the timescale involved in it, which makes controlled trials almost impossible. The result of this is
that evidence for the concepts of depression in long-term psychoanalysis can be hard to find (although this is slowly changing – see Fonagy, 2000).

However, shorter-term psychotherapies based on psychoanalytical concepts have been developed. There is more research on these, in part because their nature (e.g. shorter timescale) makes them more applicable to currently used research methodologies (e.g. comparative outcome studies). Interpersonal therapy (IPT; Klerman, Weissman, Rounsaville & Chevron, 1984) is a brief therapy for depression based on the interpersonal school of psychoanalysis (e.g. Meyer, 1957; Sullivan, 1953). The concepts behind IPT, and the evidence for them, will be used to outline a psychoanalytic approach to depression.

IPT is a brief, time-limited therapy for depression. It focuses on the relationship between the onset and maintenance of depression and interpersonal events. It aims firstly to alleviate the symptoms of depression and secondly to improve patients’ general interpersonal relations. IPT focuses on one of four interpersonal areas: unresolved grief, role transitions, interpersonal role disputes and interpersonal deficits. It works with patients to renegotiate interpersonal difficulties associated with this area. The therapist has an active, supporting role. Therapy looks at the interpersonal origins of depression in the patient’s normal social context rather than primarily analysing the interpersonal relationship within therapy.

IPT is based on interpersonal psychoanalytic concepts (e.g. Meyer, 1957; Sullivan, 1953) and stresses the work of Bowlby (e.g. 1969). Bowlby argued that people have an instinctive drive to form relationships and stressed that powerful emotions are associated with them (e.g. love, hate etc.). The way we deal with challenges in our current interpersonal relationships is partly influenced by our early interpersonal experiences and the unconscious processes involved in them (Meyer, 1957). The interpersonal school believe that the construction of our self-identity is reliant upon our current interpersonal situation (e.g. Sullivan, 1953). Conflict and breakdown in these self-defining relationships therefore causes distress and difficulties in our general functioning, which can manifest as mental illness.

The IPT conceptualisation of depression does not make any causal claims. It simply acknowledges that depression occurs in a social context. In depression, this context involves interpersonal difficulties around the time of onset of the depressive episode. The symptoms of depression then maintain the episode by disrupting the individual’s communication and interaction (e.g. through social withdrawal), which further disrupts current relationships.
To summarise, general psychoanalytical concepts in depression include loss (related to self esteem), unconscious processes, instinctual drives and conflict. Emotion is placed at the core of our functioning. IPT is based on a number of these core psychoanalytic principles, such as the drive for attachment, the notion of loss (in interpersonal settings) and the importance of relationships and emotion. Factors in this interpersonal conceptualisation of depression include the importance of interpersonal relationships to our functioning, the existence of interpersonal difficulties at the onset of and during a depressive episode and the disruption depressive symptoms cause to interpersonal relationships (which maintains the depression).

Evidence for Psychoanalytic Concepts of Depression

As stated earlier, research in areas of long-term psychoanalysis has been rare and generally of poor quality by current standards (Bateman & Holmes, 1995). This is changing (see Fonagy, 2000), but research on briefer therapies based on psychoanalytic concepts is more prevalent. The IPT conceptualisation of depression stresses the importance of relationships (or attachments) in our emotional and general functioning, the presence of interpersonal stressors at the onset of depression and the disruption in interpersonal relationships caused by depressive symptoms. But what evidence is there to support these concepts?

John Bowlby developed a theory of attachment using scientific methodology, which he felt psychoanalysis had moved away from since the time of Freud (e.g. Bowlby, 1969). He stressed the important role of relationships in our emotional functioning. He argued that we are born with a number of instinctual behaviour patterns (crying, smiling, vocalising) and areas of perceptual interest (e.g. faces, voices) that enable us to begin forming reciprocal relationships, particularly with a "primary care giver" (PCG). Separation from the PCG (i.e. disruption in the interpersonal relationship) causes distress and anxiety in the infant. Thus we are instinctively and biologically motivated to seek attachments with others and difficulties in this can cause us emotional distress. As we develop the importance of separation diminishes, and more abstract qualities (e.g. warmth) become important for our emotional functioning. Bowlby concluded that to maintain mental health in children warm, intimate and continuous relationships are important (Bowlby, 1953).

The importance of relationships continues throughout the life cycle. Frequent disruption in these earlier interpersonal situations can impair our ability to relate to others. This can set up patterns of relating which continue to cause emotional distress. Thus, disruption in
attachment bonds (interpersonal relationships) in adulthood can lead to emotional distress and the developmental of mental health problems.

Stader and Hokanson (1998), in their study of a non-clinical student population, reported that ratings of interpersonal stress were higher on the day before depressive symptoms increased. Frank and colleagues (Frank, Anderson, Reynolds, Ritenour & Kupfer, 1994) found that psychological stress plays an important role in the timing of the onset of depressive episodes, even amongst people who have had multiple depressive episodes. Mazura and colleagues (Mazura, Bruce, Maciejewski, & Jacobs, 2000) described adverse life events as a "potent factor in predicting depression". Thus, there appears to be a body of evidence that supports the existence of interpersonal stress around the onset of depression. This evidence is further supported because a causal relationship is not implied in IPT.

The link between symptoms of depression and further disrupted relationships appears to have face validity. For example, DSM-IV (American Psychiatric Association, 1994) describes symptoms of depression that would appear to disrupt interpersonal functioning (e.g. increased irritability, withdrawal, possible hypersomnia etc.). Frank and Spanier (1995) reviewed much of the evidence for the concepts of depression in IPT. They found support for the notion that the symptoms of depression are disrupting to an individual's social environment. Their review also covered the evidence for interpersonal stress at onset of a depressive episode, which they also found evidence for.

As with cognitive behavioural concepts, studies showing evidence for the effectiveness of IPT in treating depression could show support for the concepts behind it. One such study compared IPT and an anti-depressant (both alone and in combination) with a control group (Weissman et al., 1979). They found that at the end of the treatment programme there was no difference between the anti-depressant and IPT groups in levels of symptom reduction. Further, both were more effective than the control group.

To summarise, there is evidence to demonstrate that attachments to others can affect our emotional functioning and that we have an instinctual drive to seek these relationships (e.g. Bowlby, 1969). Interpersonal distress is also related to the onset and course of a depressive episode (e.g. Frank, Anderson, Reynolds, Ritenour & Kupfer, 1994; Stader & Hokanson, 1998). Outcome trials have also shown that IPT is an effective treatment with people who are clinically depressed (Weissman et al., 1979).
**Discussion**

The concepts behind cognitive behaviour therapy and IPT, and the evidence for them, have been outlined. From this it can be seen that there are some importance differences between the two models.

Firstly, whilst cognitive behavioural theory outlines how depression is caused and maintained, the interpersonal theory makes no claims about causation. It views a person's current interpersonal status as vital to their self-identity. Depression is a manifestation of difficulties in this interpersonal area. The concept of causation has important implications for research studies, as a causal link is very hard to demonstrate. Prospective studies could possibly provide evidence, but to use these researchers would need to know who is going to become depressed in the future. Some prospective studies, outlined earlier, have made links between depressive symptoms and cognitive behavioural concepts in non-clinical populations. However, this does not necessarily transfer to clinical populations. Therefore, the evidence for the causal claims of the cognitive behavioural theory is somewhat weakened.

Another important difference between the two models of depression is how they relate to other areas of our global functioning. The theory behind IPT is connected to our development, motivation and social environment. However, the cognitive behavioural theory is linked mainly with psychopathology. Development is only considered from the point of view of development of dysfunctional beliefs, motivation is only considered from the point of view of personality dimensions that are risk factors for depression and the environment is considered only as a source of critical incidents that trigger depression. Thus, insufficient account is taken of the environmental difficulties people with depression encounter. The evidence supporting the cognitive behavioural model is therefore slightly weakened by its isolation from other aspects of our biopsychosocial functioning. On the other hand, the interpersonal model takes little account of internal cognitive processes. It also seems that the current model would have to make some fundamental changes to incorporate these cognitive factors. Therefore, the case supporting this interpersonal theory, as it stands at present, is also weakened.

Despite these important differences, there are also a number of similarities between the two models. Firstly, both argue that depression develops from "normal" psychological processes. They are also similar in the way they use their concepts in therapy. They are both short-term therapies in which the therapist plays an active role. The focus is on the patient's current,
conscious functioning. The primary goal of therapy is to relieve current depressive symptoms. Further, they both aim to do this through the development of new skills. In CBT these are ways of identifying and challenging negative cognitions, whilst in IPT they are ways of renegotiating positions in interpersonal conflicts. Although both stress the patient’s current situation, they also recognise the important role of the past – in developing dysfunctional beliefs in CBT and in the setting up of dysfunctional patterns of relating in early life in IPT.

Another similarity between the theories is that both have outcome research supporting their efficacy in the treatment of depression. Further, studies comparing IPT and CBT treatment groups have found that they are effective to a similar degree in producing significant pre-treatment to post treatment improvements (e.g. Elkin et al., 1989). In their wide-ranging review of psychotherapy research, Roth and Fonagy (1996) looked at which psychotherapies demonstrated benefits in people with depression. They concluded that:

“...CBT emerges across studies as a powerful and useful method for treating the acute symptoms of depression. IPT also emerges as valuable in a number of contexts, both in tackling severe symptoms and as an adjunct to pharmacological treatment.”

(pp. 100-101)

In summary, the concepts behind IPT and cognitive behavioural therapy have a number of difference and similarities. Outcome studies have demonstrated they both work well in practice in treating depression. There is also supporting evidence for a number of the concepts on which the models are based. However, as noted above, both the current models have certain limitations. These will affect future areas of research and thus how these models will develop.

Conclusions

The current empirical standing of the concepts behind CBT and IPT has been outlined. There is research supporting the existence of negative thoughts, dysfunctional beliefs and the personality dimensions of sociotropy and autonomy in the cognitive behavioural model of depression. In the interpersonal model there is evidence supporting the importance of relationships in our emotional functioning, the presence of interpersonal difficulties at the onset of and during depressive episodes and the maintenance of interpersonal distress by depressive symptoms also have research supporting them. Outcome research for IPT and cognitive behavioural therapy in depression is also promising. However, much of the
evidence for the concepts behind both of the theories is far from conclusive. It would seem
the most support is for the existence of negative automatic thoughts in maintaining depression
and the existence of interpersonal difficulties at the onset and during the course of a
depressive episode. So what implications does this have for future research and practice in
depression?

The evidence for the two models, at both the conceptual and practical levels, is quite similar.
They both have strengths and weaknesses. This may seem puzzling in light of the fact that
there are important differences in the concepts behind them. Is their effectiveness therefore
due to some as yet undetermined common factor? This does not have to be the case. At the
very beginning of this essay, the variability in the presentation of depression was reported.
Also, even in the most favourable outcome studies, a high percentage of depressed clients
have poor outcomes. It would seem, therefore, that everyone in the depressed population is
not treatable by just one model of depression. In an effective psychotherapy, the therapist is
able to respond to the varying needs of the client. Thus, a combination of treatment options
needs to be available. Therefore, the fact that there is evidence supporting both the
psychoanalytic and the cognitive behavioural approaches does not in itself undermine the
models. It may just be a reflection of variation within the depressed population.

There is at least one other consideration when explaining the similar levels of evidence for
these two models. This is the possibility that some of these interpersonal and cognitive
factors are interdependent. Perhaps, therefore, research and conceptual developments should
be directed at integrating the concepts from these models that have the best evidence-base.
There is already research supporting models of depression that integrate psychoanalytic and
cognitive behavioural concepts (e.g. Kwon, 1999; Kwon & Lemon, 2000). The evidence
reviewed in this essay suggests that models incorporating some of the concepts behind both
cognitive behavioural therapy and IPT may be appropriate for future research in the treatment
of depression.

In summary, the concepts behind a psychoanalytic approach to depression (IPT) and cognitive
behavioural approaches to depression have been outlined. The evidence for some of these
core concepts has also been reviewed. Similarities and differences in both the models and
their evidence-base were examined. Finally, some implications for future research and
development in psychological approaches to depression were suggested. It was felt that
variability in approaches to depression was beneficial to both clinical services and the
depressed population. Further, research on integrating psychoanalytic and cognitive behavioural concepts could be of benefit in the treatment of clinical depression.
References


People with Learning Disabilities Essay

“All challenging behaviour in individuals with learning disabilities has a communicative function and can be explained by deficits in communication skills”. Critically discuss this proposition

Completed in Year 1
Introduction

The World Health Organisation (WHO) has defined a learning disability as a:

"...state of arrested or incomplete development of mind...[that involves]...significant impairment of intelligence and social functioning...[and is]...manifested during the developmental period."

(WHO, 1992; cited in Emerson, Hatton, Felce & Murphy, 2001)

In practice, significant impairment of intelligence has been taken to mean an intelligence quotient (IQ) that is less than 2 standard deviations below the mean (i.e. an IQ under 70; American Psychiatric Association, 1994). The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (American Psychiatric Association, 1994) defines a significant impairment of social functioning as deficits in at least two of the following skill areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academics, work, leisure, health and safety.

It has been estimated that between 580,000 and 1,750,000 people in the UK have a learning disability (Emerson, Hatton, Felce & Murphy, 2001). This large group of people have the same health needs as the general population, but also require additional input from health services. One area where this additional input has been directed is in the management of what has been termed "challenging behaviour". This has been defined as:

"...culturally abnormal behaviour of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities."

(Emerson, 1995)

Challenging behaviour has sometimes been understood as simply aggressive or self-injurious behaviour. However, Emerson’s (1995) definition outlines that it is any behaviour that presents a challenge to those providing services. Estimates of the prevalence of challenging behaviour in the learning disabled population vary due to the lack of consensus over what should be included in the figures (e.g. psychiatric disturbance, autism). However, it is
generally agreed that challenging behaviour is relatively common in people with learning disabilities (e.g. Harris, 1993).

Historically, many people thought that the behaviour of those with a learning disability had little potential for change. However, in the 1960s challenging behaviours were successfully changed through interventions based on psychological theories (e.g. Lovaas, Freitag, Gold & Kassorla, 1965; cited in Emerson, 1995). This primarily involved the application of the theory of operant conditioning (e.g. Skinner, 1953). This argues that all behaviour is determined by the positive and negative reinforcers provided by the social environment. Positive reinforcers increase the likelihood of a behaviour by adding a favourable consequence and negative reinforcers increase the likelihood of a behaviour by removing an aversive consequence. The early attempts to apply this theory to challenging behaviour aimed simply to reduce the occurrence of undesired behaviours by manipulating their consequences (e.g. extinction programmes).

Despite their successes, these early interventions rarely produced generalised behavioural change, did not aim to improve quality of life, often used aversive techniques and did nothing for the social status of people with learning disabilities (Clements, 1992). These criticisms encouraged the development of “constructional” approaches to challenging behaviour (e.g. Goldiamond, 1974). These recognised that challenging behaviours often had adaptive functions for the individual. Therefore, rather than trying simply to extinguish behaviours, they used education and positive reinforcement to teach alternative skills.

One constructional approach that has been developed is based on the “communication hypothesis” (e.g. Carr & Durand, 1985; Donnellan, Mirenda, Mesaros & Fassbender, 1984). This conceptualises challenging behaviour as functional communication. Interventions based on this approach aim to teach socially acceptable means of communicating the same needs. If this theory could be usefully applied to all challenging behaviour, it would support the title proposition.

This essay aims to critically analyse the title proposition in terms of how useful it is for clinical practice with people with learning disabilities. It will begin by outlining evidence that supports the communication hypothesis. It will then examine evidence that suggests there are other useful ways of conceptualising challenging behaviour. A final section will
examine some service issues that would arise if the title proposition were adopted, before conclusions are drawn based upon the evidence that has been presented.

The Communication Hypothesis

As outlined in the introduction, the communication hypothesis uses a constructional approach to challenging behaviour. It aims to displace challenging behaviours by replacing them with ones that are functionally equivalent. Its theoretical basis argues that people with learning disabilities are motivated to act because of some unmet need. Due to deficits in communication skills, these needs are indicated through a limited repertoire of behaviours. These may include behaviours that services find challenging (e.g. hitting others, screaming). If a behaviour results in the individual’s need being met, the “message” it conveyed would appear to have been understood. The behaviour is therefore positively reinforced, which increases the likelihood of it being used again the next time the individual is in the same situation.

Interventions based on the communication hypothesis first identify the function that the challenging behaviour performs for the individual. This allows understanding of the message being communicated (e.g. “I am bored”, “I need help”). Communicative functions of challenging behaviour that have been identified in the research literature include escaping from task demands (e.g. Lalli, Casey & Kales, 1995), gaining attention (e.g. Carr & Durand, 1985) and gaining access to preferred items (e.g. Bird, Dores, Moniz & Robinson, 1989). Once the function has been identified, a socially acceptable alternative is taught to the individual. This should then displace the challenging behaviour. However, for displacement to occur, the alternative needs to be both functionally equivalent to and more efficient than the challenging behaviour (Emerson, 1995).

It is important that behaviours are clearly defined in relation to the context in which they occur. This is because the same behaviour may serve different communicative functions not only between individuals, but also across time and environments for the same individual. Thus, different messages may be inferred from the same behaviour by the same individual in different situations. For example, someone may be observed to shout out. Only an understanding of whether the person has just been surprised, is in pain or is trying to get the attention of someone far away will allow the communication to be inferred.
There is research evidence to support the proposed relationship between challenging behaviour and communication skills. An estimate that between 50% and 90% of people with learning disabilities have communication difficulties (Van der Gaag, 1998) could explain the relatively high level of challenging behaviour in the learning disabled population. It was found that in 15 adults with a learning disability behavioural problems were more frequent in those with a greater degree of communication difficulty (Chamberlain, Chung & Jenner, 1993). It has also been reported that there are more behaviour problems in people with learning disabilities who have good understanding but no speech than in those with good speech (Bott, Farmer & Rhode, 1997).

Other research has studied the effectiveness of interventions based on the communication hypothesis. Mirenda (1997) reviewed 52 case studies where “functional communication training” (FCT) was used as an intervention for challenging behaviour in people with learning disabilities. FCT involves identifying the communicative functions of challenging behaviour and teaching functionally equivalent communication skills. Mirenda (1997) reported that there was a reduction in challenging behaviour in all but four of the participants. In two of these exceptions, the authors of the study felt poor implementation of the intervention by staff affected the outcome. In the other two cases, the authors hypothesised that the alternative taught was less efficient than the challenging behaviour.

The communication hypothesis relates challenging behaviour to communication skills. Interventions aimed at increasing general communication skills, rather than targeting specific behaviours, may also therefore reduce challenging behaviour. Thurman (1997) described a residential unit for six men with learning disabilities that adopted a communication-centred approach. This involved additional staff training, encouraging the use of functional signs and symbols and creating a communication policy. The author looked at the impact of this approach on one of the residents. It was found that over a five-year period his challenging behaviour decreased and his communication opportunities and skills increased. Rowland and Treece (2000) carried out another longer-term study. They looked at the change in challenging behaviour of four men with learning disabilities in the six years following their move into a specialist challenging behaviour unit. The unit emphasised the role of communication in challenging behaviour. In the period of the study, behavioural improvements occurred simultaneously with communication development. It was felt that the challenging behaviours served a significant communicative function for the individuals’ exhibiting them.
Evidence therefore exists to support a relationship between level of communication skills and level of challenging behaviour. Further, interventions that teach specific communication skills and those that increase general communication opportunities have both resulted in reductions in challenging behaviour. However, this essay aims to critically analyse whether the communication hypothesis is a useful conceptualisation for all challenging behaviour. Evidence that suggests there are other explanations for at least some challenging behaviour therefore needs to be examined.

Before the discussion moves away from the communication hypothesis, a theoretical issue will be briefly outlined. The communication hypothesis is based on a pragmatic view of behaviour. This position is summarised by the following statement:

"No matter how one may try, one cannot not communicate. Activity or inactivity, words or silence all have message value: they influence others and these others, in turn, cannot not respond to these communications and are thus themselves communicating."

(Watzlawick, Beavin & Jackson, 1967, p.49; cited in Donnellan, Mirenda, Mesaros & Fassbender, 1984)

This implies that all challenging behaviour must have message value because all behaviour has message value. Thus, all challenging behaviour must have a communicative function, as the title proposition states. However, an alternative view is that communication is:

"...an intentional transmission of meaning in a formal code between people who share that code"

(Coupe & Jolliffe, 1988, p.104; cited in Bradshaw, 1998)

This definition stresses the importance of intention. This debate about the definition of communication has led some to question the theoretical basis of the communication hypothesis (e.g. Emerson, 1992). This essay will not take this debate further, as it aims to critically evaluate the title proposition in terms of how useful it is for clinical practice. However, it is important to note that considerable debate about the theoretical nature of communication, and thus the basis of the communication hypothesis, still exists.
Setting Events

Setting events are antecedent factors that influence the relationship between the environment and challenging behaviour. They include a variety of both internal (e.g. pain, physical health) and external (e.g. who is present, environment) factors. Interventions based on the communication hypothesis do not aim to change setting events. Evidence suggesting setting events are a useful way of conceptualising some challenging behaviour in the learning disabled population would therefore appear to oppose the title proposition.

There is evidence that in the general population, some challenging behaviours increase with certain setting events. For example, aggression increases with heat (e.g. Griffit, 1970) and pain (e.g. Berkowitz, 1983). Allen (2000) argued that the precipitators of challenging behaviour in the learning disabled population are probably the same as in the general population. Further, Emerson (1995) outlined research linking a number of setting events with challenging behaviour. These included sleep, caffeine intake, the menstrual cycle and critical comments from others. However, the communication hypothesis can explain the influence of these setting events. It stresses the importance of the relationship between challenging behaviours and the context in which they occur. Certain setting factors may make a challenging behaviour more or less likely. For example, a hot environment may make it harder for someone to cope with task demands and thus lead to an increase in behaviours that allow escape from those demands. Therefore, although altering these setting events may influence the occurrence of challenging behaviour, if it did occur it could still be conceptualised in terms of its communicative function.

However, with other setting events the communication hypothesis appears less useful. Geyde (1989) investigated the relationship between aggression and frontal lobe seizures. These seizures do not involve loss of consciousness and their presentation varies widely across between individuals. They can therefore be hard to recognise. Geyde examined ictal phenomena (phenomena associated with seizure activity) and aggression in 20 subjects. It was concluded that some aggressive behaviour in the sample was involuntary and due to frontal lobe seizures. Chung and Cassidy (2001) also examined the relationship between epilepsy and challenging behaviour. They compared staff reports of challenging behaviour on learning disabled epileptics and non-epileptics. They found that those with epilepsy tended to produce more challenging behaviour than those who did not have epilepsy.
Others have examined the role of neurobiological processes in maintaining self-injurious behaviour. One review (Thompson, Symons, Delaney & England, 1995) reported that a neurotransmitter (Beta-Endorphin) released during repeated trauma (e.g. self-injurious behaviour) is closely related to morphine - it has analgesic properties, is associated with an elevated mood state and may lead to dependency. The authors of the review also noted similarities between some self-injurious behaviour and addictive behaviour in those who self-administer cocaine and morphine. They concluded that some self-injurious behaviour is maintained by attempts to self-administer addictive neurochemicals. It is the experience of this that can make self-injurious behaviour a setting event. A study that used both FCT and an opiate antagonist as an intervention (Symons, Fox & Thompson, 1998) reported that the largest reduction in self-injurious behaviour occurred when they were combined.

Therefore, the communication hypothesis can usefully account for the influence of some setting events on challenging behaviour. However, in other cases, interventions aimed at reducing epilepsy or disrupting self-administration of addictive neurochemicals would appear to be a more useful approach.

Mental Health Problems

One cause of challenging behaviours in the general population is psychiatric disorders. Evidence suggests that the prevalence rate of mental health problems in the learning disabled population is above that of the general population (Lund, 1985; cited in Prosser, 1999) and people with learning disabilities have a higher risk of developing mental health problems (Borthwick-Duffy, 1994). Further, it is thought that these mental health problems often go undiagnosed (Patel, Goldberg & Moss, 1993). Some challenging behaviours in people with learning disabilities could therefore represent the atypical presentation of an underlying psychiatric disorder or may be secondary features of psychiatric disorders (Emerson, Moss & Kiernan, 1999).

There is evidence to support the link between psychiatric disorders and challenging behaviours. One study looked at psychiatric symptoms in a sample of 320 learning disabled adults (Moss et al., 2000). This consisted of a group described as challenging in a previous study (n=234) and an age-matched control group who did not have challenging behaviour (n=86). Psychiatric symptoms in both groups were measured using the Psychiatric Assessment Scale for Adults with Developmental Disabilities Checklist (Moss et al, 1998).
This was completed by informants who knew the subjects well. It was found that psychiatric disorders were significantly related to challenging behaviour. This was particularly true of depression, which was four times as prevalent in those whose challenging behaviour was rated as demanding than those with no challenging behaviour. The authors concluded that identifying and treating psychiatric disorders could reduce challenging behaviour.

This evidence appears to support the idea that some challenging behaviour can be usefully conceptualised in terms of a psychiatric disorder. However, it has been suggested that what may actually occur is that psychiatric disorders can be considered as a setting event. They provide increased motivation for the use of challenging behaviours that serve a communicative function and have been established through operant reinforcement (Emerson, Moss & Kiernan, 1999). For example, the presence of depression may make task demands more aversive for an individual. Thus, the motivation to use behaviours that gain escape from these demands is increased. There are also great difficulties with identifying mental health problems in the learning disabled population. There is considerable variation in estimates of their prevalence (Borthwick-Duffy, 1994). Further, this variation is not uniform across different mental health problems. Therefore, some appear more prevalent than in the general population and some less so (Prosser, 1999). When considering how useful it is to consider challenging behaviours in terms of psychiatric disturbance, this confusion becomes an important factor.

Despite these arguments, it still appears that in clinical practice it can be more useful to treat the underlying psychiatric problem. This is an attempt to address the cause of the individual’s distress rather than just focussing on one symptom or secondary feature of it.

Sexual Abuse

The position of people with learning disabilities in society, the environments in which they live and the relatively large number of communication impairments they have make them particularly vulnerable to abusive practices. Psychological and physical abuse are both common within this client group, but most of the focus in this area is on sexual abuse (Emerson, Hatton, Felce & Murphy, 2001). Fenwick (1994) reviewed the literature on sexual abuse within the learning disabled population. It was found that little research had been carried out, and what had been done mainly consisted of single case studies. It was therefore unclear how many learning disabled people who displayed challenging behaviour had
experienced sexual abuse at some point in their lives. One attempt to estimate prevalence rates looked at 185 people with learning disabilities who were referred for sex education (McCarthy & Thompson, 1997). It was found that 61% of women and 25% of men reported being sexually abused.

Christo (1997) reviewed research on the psychological consequences of child sexual abuse on the general population. A number of behavioural and emotional effects were identified. These included anger, aggression, self-harm, withdrawal, anxiety and deviant sexual activities. All of these could be either setting events (e.g. sleep disturbance, raised anxiety levels) or challenging behaviours in themselves according to Emerson’s (1995) definition. Allen (2000) claimed that the precipitators of challenging behaviour in the learning disabled population are probably the same as in the general population. It therefore seems reasonable to assume that the effects of sexual abuse are the same for people with learning disabilities as other survivors. In support of this, it has been claimed that withdrawal, behavioural difficulties and emotional distress are common in learning disabled people who have been sexually abused (Sobesy, 1994; cited in Moss, 1998).

Generally, service responses to sexual abuse in people with learning disabilities are very poor (McCarthy & Thompson, 1997). However, there are a number of ways that learning disability services can approach the issue of sexual abuse. These include developing policies and procedures, providing information about the impact of abuse to care staff and offering therapy to survivors themselves. When considering what approaches are useful in this area, what is useful for the individual must not be forgotten. Any interventions aimed solely at challenging behaviours that are the result of sexual abuse would ignore the emotional impact such a trauma can have. They may, in fact, maintain feelings of guilt and shame by concentrating on the “problem” behaviours the person has.

The behavioural sequelae of sexual abuse may serve the communicative function of indicating distress to others. However, intervention aimed at teaching alternative communication skills to displace challenging behaviours does not seem appropriate. It seems to lack empathy, neglecting the emotional side of people with learning disabilities. Therefore, the title proposition appears particularly unhelpful for clinical work in this area.
Behavioural Phenotype

Recently, there has been a renewal of interest in the influence of genetics on behaviour (e.g. Plomin, 2001). A behavioural phenotype is a set of behaviours associated with a genetic syndrome. It has been defined as:

"...a characteristic pattern of motor, cognitive, linguistic and social abnormalities which is consistently associated with a biological disorder."
(O'Brien & Yule, 1995; cited in Holland, 1999)

Describing a behaviour as part of a behavioural phenotype does not mean it is inevitable. The environment still has a role to play, but the genetic influence makes the behaviour more likely to occur. It may be useful to conceptualise some challenging behaviour in people with learning disabilities as part of a behavioural phenotype rather than in terms of its communicative function.

A range of syndromes are associated with challenging behaviours. These include Tourette’s syndrome, Prader-Willi syndrome, and Rett’s syndrome. There is not room to discuss all of these here. Instead, challenging behaviour associated with two syndromes will be outlined – Lesch-Nyhan syndrome and autism.

Deb (1998) reviewed the behaviours seen in those with Lesch-Nyhan syndrome. This affects between 1 in 10 000 and 1 in 380 000 live births, nearly all of them males. It is caused by a disorder of the X chromosome, which results in an almost complete lack of a certain enzyme (hypoxanthine phosphoribosyltransferase). This leads to high levels of uric acid in the blood and disorders in the functioning of the central nervous system.

Self-injurious behaviour occurs in all people with Lesch-Nyhan syndrome. The behavioural phenotype begins to become apparent in the first few months of life, when involuntary movements and developmental delay can be noticed. Then, between two and three years of age, self-injury begins. A main feature of this is biting of the lips, the inside of the mouth and fingers. This occurs to such an extent that it results in significant tissue loss. Other challenging behaviours include verbal and physical aggression and hitting the ears and head.
Olson and Houlihan (2000) reviewed the use of behavioural interventions with those who have Lesch-Nyhan syndrome. They found that a number of interventions had successfully reduced the occurrence of self-injurious behaviour. For example, one study (Grace, Cowart & Matson, 1988) combined positive reinforcement, time out and self-instruction in an intervention across two settings (hospital room and bedroom). Within three days of intervention, self-injurious behaviour had reduced from up to sixty bites in a thirty-minute session to zero bites. Further, a nineteen-week follow-up showed that the behaviour had not recurred.

Autism affects at least one in one thousand children and adults (Happe, 1999). It is considered to compose a spectrum of difficulties, which incorporate a triad of impairments: social impairment, communication impairment and imagination impairment. These lead to difficulties interacting and empathising with others, a failure to understand the social purpose of communication, a limited range of interests and activities and an intense dislike of change. There is also an increased risk of challenging behaviour. This can include aggression and self-injurious behaviour, both of which often occur in response to anxiety or an unusual response to sensory stimuli.

Interventions for people with autism involve a range of techniques. These include the use of pictorial forms of communication, a structured day, carefully planning changes and maintaining a calm and safe environment. A number of comprehensive intervention programmes have been designed (e.g. TEACCH; Schopler & Mesibov, 2000). These tend to be based around communication, but incorporate a range of other ways of managing challenging behaviour and the triad of impairments.

Therefore, it appears some challenging behaviour is part of behavioural phenotypes. However, there is evidence this can still be changed through interventions. The communication hypothesis might therefore be a useful way of conceptualising some of this challenging behaviour, especially in syndromes where impairments in communication are emphasised. The title proposition, on the other hand, argues that all challenging behaviour can be explained by deficits in communication skills. This seems a less useful approach, which ignores the relationship between behaviour and genetic syndrome.
Service Issues

So far, this essay has focused on different ways of usefully conceptualising challenging behaviour in clinical practice. The title proposition would raise other issues if it were used in learning disability services. Some of these will now be considered. Evidence has been presented that suggests the communication hypothesis can be a very useful way of informing interventions. However, incorporating the title proposition into clinical practice would involve conceptualising all challenging behaviour in people with learning disabilities in terms of deficits in communication skills. Other research suggests this would deny the client group access to other interventions that might be more suited to their individual needs (e.g. treatments for mental health problems). This would also oppose current policy, which emphasises that people with learning disabilities should be given a choice over the interventions they receive (Department of Health, 2001). Thus, the title proposition does not seem to fit with this aspect of current learning disability service philosophy.

NHS policy (Department of Health, 2001) also emphasises that people with learning disabilities should not be marginalized or excluded from society. However, challenging behaviour in the general population is not currently understood solely in terms of deficits in communication skills. It is attributed to a number of factors, including mental health problems, personality and environmental conditions. Therefore, the suggestion that all the challenging behaviour of people with learning disabilities has a communicative function marginalises and devalues them by treating them as a homogenous group of “different” people. Again, therefore, the title proposition appears to clash with service philosophy. It would appear more appropriate to conceptualise challenging behaviours in the same way as in the general population, but acknowledge that there are additional risk factors specific to the client group.

In the introduction, a learning disability was defined as an IQ score below 70 with an impairment in social functioning. These factors are measured via formal assessments, such as the Wechsler Adult Intelligence Scale, third Edition (WAIS-III; Wechsler, 1997). However, such assessments are not exact instruments. For example, the WAIS-III gives a 95% confidence range of IQ score, which allows for variations of a number of IQ points. In practice, this has contributed to difficulties in diagnosing people with learning disabilities. The introduction also stated the commonly used definition of challenging behaviour of
Emerson (1995). This stresses that challenging behaviours are "...social constructions defined by their social impact" (Emerson, Moss & Kieman, 1999). In practice, this has contributed to variations in what has been considered to be challenging behaviour. The variations in the use of these terms in clinical practice do not mesh well with the absolute statement in the title proposition (i.e. "All..."). It would seem, therefore, that it is not a useful proposition for clinical services.

Although the title proposition does not appear to fit well with current service policy, it seems the communication hypothesis could. It conceptualises challenging behaviour as a communicative challenge for the service rather than as a problem that individuals carry around with them. This might encourage more constructive approaches to challenging behaviour. Interventions based on the communication hypothesis are also aimed at improving the quality of life of people with learning disabilities. They teach new skills, which can increase the influence that someone has over their environment by facilitating communication. Thus, they can encourage choice, independence and a more valued social role.

**Summary and Conclusion**

This essay has examined whether the title proposition is a useful one for clinical practice. It has outlined evidence that supports the conceptualisation of challenging behaviours in terms of their communicative function. It has also looked at evidence that suggests there are other useful ways of conceptualising challenging behaviour. Not all possible approaches could be considered, as the space available did not allow such a broad discussion. However, conceptualising challenging behaviours in terms of setting events, mental health problems, behavioural phenotypes and abuse was proposed. A final section looked at the impact the title proposition would have on clinical practice in the field of learning disabilities.

In conclusion, it appears the title proposition is not useful for clinical practice. It assumes that the causal and maintaining factors of challenging behaviour can be usefully conceptualised in the same way for all people with learning disabilities. However, the research evidence presented indicates this is not the case. Other useful ways of conceptualising challenging behaviour include setting factors, mental health problems, genetic syndromes and as sequelae of sexual abuse. Thus, adopting the title proposition would deny access to other useful interventions for challenging behaviour. It would also be
difficult to incorporate it into current learning disability services. There are significant variations in how some of its terms are applied in practice. It also appears to conflict with current NHS policy by treating people with learning disabilities as a homogenous group, discouraging social inclusion and preventing choice.

However, this conclusion does not mean that the communication hypothesis is not useful for clinical practice. Evidence has been presented that shows it can be an effective intervention for some challenging behaviour. This emphasises the importance of thorough assessment in learning disabilities services, in which interventions from a variety of sources can be considered. This process can then identify whether conceptualising challenging behaviour in terms of its communicative function is the most useful approach for the individual concerned. It can also decide whether this should occur in isolation or as part of a broader intervention plan.
References


Anxiety disorders in children are fundamentally different from anxiety disorders in adulthood. Discuss with reference to the theory and treatment of two anxiety disorders.
Introduction

The emotion of anxiety has physiological (e.g. increased breathing rate, heart rate and blood pressure), affective (e.g. fear), cognitive (e.g. hypervigilance) and behavioural (e.g. increased activity) effects on the individual. These effects are thought to prepare us to fight, flight, freeze or faint when we are faced with danger (Beck & Emery, 1985). Anxiety is therefore an adaptive reaction that plays an important part in our survival. However, sometimes the level of anxiety felt by an individual is disproportionate to the risk of danger faced and/or continues when no danger is present. For some people, this type of anxiety response becomes persistent, causes distress and impairs normal functioning. In these instances the person is said to be suffering from an anxiety disorder.

The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV; American Psychiatric Association, 1994), describes a number of anxiety disorders. These include: panic disorder (with and without agoraphobia); specific phobias; social phobia; obsessive-compulsive-disorder; posttraumatic stress disorder; generalised anxiety disorder; separation anxiety disorder. These disorders are differentiated by the stimuli that elicit the anxiety response, the situations in which the anxiety response occurs, the topography of the anxiety response and factors that can be clearly identified in the aetiology of the anxiety disorder (e.g. a specific traumatic event).

Research has attempted to estimate the prevalence of anxiety disorders. In a study that incorporated a sample of over 8000 people from a wide geographical area that was representative of the US population, it was estimated that anxiety disorders had a lifetime prevalence of 24.9% and a 12-month prevalence of 17.9% (Kessler et al., 1994) in those aged 15-54. A UK survey of over 10 000 households estimated a one-week prevalence of anxiety disorders in the 16-64 age group of 13.9% (Jenkins et al., 1997). Costello and Angold (1995) reviewed the research on the prevalence of anxiety disorders in children. They reported that research in this area was limited, but findings ranged from 5.7% to 17.7%. The prevalence figures reported in these studies indicate that the understanding and treatment of anxiety disorders is an important issue for mental health services. They also show that anxiety disorders are a problem throughout the lifespan, affecting both the child and adult populations. Psychological theories and treatments for anxiety disorders have largely been developed from research and clinical practice with the adult population (Lodge & Tripp, 1995). These approaches have then been applied to children thought to be suffering from similar disorders. However, it is unclear if there is a rationale for doing this. Childhood is a time of great and
rapid development, including changes in our cognitive and physiological functioning (e.g. Carr, 1999). Is it therefore possible to conceptualise and treat anxiety disorders in children in the same way as in adults? This essay aims to address this question.

The literature on anxiety disorders is extensive and it would not be possible to incorporate all of this information in the space allowed in this essay. The Department of Health (2001), in a recent document on treatment choice in psychological therapies in the adult population, reported that:

"Anxiety disorders with marked symptomatic anxiety (panic disorder, agoraphobia, social phobia, obsessive compulsive disorders, generalised anxiety disorders) are likely to benefit from cognitive behaviour therapy.” (p.3)

This essay will therefore look only at cognitive behavioural interventions. It will outline cognitive behavioural approaches to two anxiety disorders in the adult population and then examine how they have been applied to children. Developmental research will also be considered to see if this is compatible with the application of adult cognitive models to children. The conclusion will outline whether it is useful to conceptualise anxiety disorders in children and adults as similar or as fundamentally different.

The two anxiety disorders that will be discussed are obsessive-compulsive disorder (OCD) and panic disorder. The cognitive model of panic is well developed and has generated a large amount of research (Clark, 1997). The cognitive model of OCD is less well developed but continues to be the subject of much research and development (e.g. Clark, 2000; Salkovskis et al., 2000). Both these disorders therefore have a broad range of literature that can be examined, at least for the adult population.

**Obsessive-Compulsive Disorder in Adults**

People who suffer from OCD experience recurrent obsessions and/or compulsions (American Psychiatric Association, 1994). Obsessions are thoughts, images and impulses that are recurrent and involuntary. They are felt to be intrusive and inappropriate by the individual, thus causing them distress. On reflection the individual often accepts that their obsessive thoughts are excessive to some degree. Compulsions are voluntary behaviours, either overt (e.g. hand-washing) or covert (e.g. mental counting), that the individual uses to reduce the distress caused by obsessive thoughts or comply rigidly with a set of rules. These
Compulsions are different from the stereotypic behaviours displayed by people with autism and tics, which differ in intent, form and resultant distress (Shafran, 1998). To be classed as OCD, the pattern of thoughts and/or behaviours must be time-consuming, cause distress and impair normal functioning (American Psychiatric Association, 1994).

Recent research has indicated that OCD is more common in the general population than was once thought, with a prevalence rate of 1-1.5% (e.g. Bebbington, 1998; Kano, Golding, Sorenson & Burnham, 1988). Current treatment for adult OCD generally includes medication and/or psychological interventions (March & Mulle, 1998). The cognitive model of OCD of Salkovskis (e.g. 1985, 1999) has been widely researched and used as the theoretical basis for treatment of OCD in adults (Shafran, 1998).

Salkovskis (e.g. 1985, 1999; Salkovskis & Kirk, 1997) suggested that obsessions develop from intrusive thoughts that are common in the general population. These thoughts only become problematic if they are appraised in a particular way. Specifically, people with OCD were hypothesised to interpret intrusive thoughts as meaning they may be responsible for harm to themselves or others. This appraisal leads to changes in mood (e.g. anxiety, depression) and motivates the individual to take some sort of action in order to reduce their responsibility for harm occurring (e.g. repeated hand washing to prevent contamination following contact with others). In the short-term, this action has the effect of reducing the individual’s anxiety. However, in the longer term it has a number of counter-productive effects. The individual’s belief in their responsibility is reinforced, as they do not learn that the event they fear will not occur. This leads to a preoccupation with preventing both harm and thoughts of harm, which has the effect of making the occurrence of obsessional thoughts more likely and thus raising anxiety levels further. A cycle of intrusive thoughts raised anxiety levels and compulsive behaviours is therefore started. The individual also uses other strategies to manage their perceived responsibility for causing harm, such as avoidance and reassurance seeking. However, avoidance of situations relevant to obsessions prevents the individual reappraising the sense of threat they feel and reassurance seeking shares or passes on the responsibility to others. These strategies therefore contribute to the maintenance of the intrusive thoughts / raised anxiety / compulsive behaviours cycle. The responsibility appraisal is therefore at the heart of Salkovskis’ model and differentiates OCD from other mental health difficulties. Without it, adverse mood would occur (e.g. depression, anger, anxiety), but not an obsessive-compulsive episode.
Treatment of OCD using this model involves helping the individual form a less threatening view of their thoughts than the one that motivates their compulsive behaviour (e.g. Salkovskis, 1999). Intrusive thoughts are normalised and the individual is constructed as someone who is worried about causing harm rather than someone who causes harm. This highlights that OCD is an anxiety problem. Through discussion and behavioural experiments, the counterproductive strategies the individual uses to manage their anxiety (e.g. compulsive behaviours, avoidance, reassurance seeking) are identified. The inflated perception of responsibility is challenged through the use of responsibility pie charts and further discussion. Therapy then focuses on exposure with response prevention, which involves exposing the individual to feared stimuli in a graded fashion and preventing their usual response. This helps the individual to stop their compulsive behaviours, which are one of the key maintaining factors of OCD, and begin to perceive them as a problem rather than a way of preventing harm.

There is research evidence to support this cognitive model of adult OCD. Rachman and DeSilva (1978) found that intrusive thoughts were common in the general population. Further, these thoughts were not substantially different from obsessional thoughts in those with OCD. Trinder and Salkovskis (1994) reported that attempting to suppress intrusive thoughts increased the frequency with which they occurred. A further study looked at the link between clinical symptoms and responsibility beliefs (Salkovskis et al., 2000). It found that people with OCD were more likely to agree with statements that reflect responsibility beliefs than people without OCD. Those with OCD were also more likely to make negative responsibility appraisals when they experienced intrusive thoughts. Further, responsibility cognitions in those with OCD differed from responsibility cognitions in those with other anxiety disorders but similar anxiety levels. This suggests that responsibility cognitions are specifically related to OCD symptoms.

Research on the cognitive-behavioural treatment of OCD is in its early stages and is less developed than research on the theory (Clark, 2000). However, evidence from outcome studies does offer some further support for cognitive model. Controlled trials have indicated that cognitive-behavioural therapy improves obsessive-compulsive symptoms (Freeston et al., 1997) and is more effective than exposure alone (van Oppen et al., 1995).
Obsessive-Compulsive Disorder in Children

The presentation of OCD in children is very similar to the presentation of OCD in adults (e.g. Bolton, 1996). The diagnostic criteria are the same, except that children do not have to have recognised that their obsession or compulsions are excessive (American Psychiatric Association, 1994). It has been estimated that OCD affects 1-2% of children (e.g. Flament et al, 1988; Zohar, 1999), which is similar to the figures reported earlier for the adult population. However, there is a difference in the gender distribution of OCD in the two populations. In children males with OCD outnumber females (Gellar et al, 1998), whilst in adults there are either more females than males or an equal distribution (Bebbington, 1998).

It has been reported that OCD in children is often only recognised when it becomes severe, which is often years after onset (Swedo, Rapoport, Leonard, Lenane & Cheslow, 1989). Children often keep their OCD symptoms a secret and parental reports often underestimate prevalence and severity (Rapoport & Inoff-Germain, 2000). Therefore, few children either have a correct diagnosis or receive appropriate treatment (Flament et al., 1988). A review of the literature on OCD reported that 30-80% of adults recalled the onset of their OCD symptoms beginning before the age of 18 and 50-70% of children with OCD continue to have the disorder in adulthood (Shafran, 2001). OCD is therefore as important an issue for child mental health services as it is for adult services.

Treatments for child OCD have paralleled treatments for adult OCD, in that they typically involve medication and/or psychological interventions. Behavioural approaches have been the most widely used psychological intervention (Shafran, 1998). However, attempts to treat adolescents with OCD using cognitive theory have reported some success (e.g. Shafran & Somers, 1997). Others have also developed cognitive-behavioural treatments for use with younger children. This has mostly centred on the work of March and colleagues (e.g. March, 1995; March & Mulle, 1998). This approach is reported to use similar techniques to the cognitive-behavioural treatment of OCD with adults (i.e. cognitive restructuring and exposure with response prevention). The authors have reported positive outcomes from case studies of cognitive-behaviour therapy for children based on their protocol (March & Mulle, 1998).

Despite the apparent similarities between the cognitive behavioural treatment of OCD in younger children and adults, there are some important differences. The cognitive-behavioural techniques used with children are not derived from a cognitive model and OCD is not seen as a result of perceived responsibility for normal intrusive thoughts. Instead, OCD is
conceptualised from a medical perspective and is seen as a neurobehavioural disorder (March & Mulle, 1998). OCD symptoms are seen as the result of “short-circuits” or “hiccups” in the brain with no intrinsic meaning (March, 1995). CBT is used in conjunction with medication to manage these symptoms. It is seen as an effective method for managing the faulty brain functioning, similar to the way psychosocial interventions such as diet and exercise are used to manage diabetes (March & Mulle, 1998). However, it is not clear from the neurobehavioural model how CBT might achieve this. The model does not explain the theoretical basis of the cognitive component of the therapy, which consists of positive self-statements and attempts to externalise the OCD and “talk back” to it. This lack of clarity in the cognitive component of the cognitive-behavioural therapy makes it difficult to distinguish the approach from behavioural therapy (Shafran, 1998).

The research has therefore highlighted a number of similarities between the presentation and cognitive-behavioural treatment of OCD in children and adults. Diagnostic criteria are very similar (American Psychiatric Association, 1994) and a behavioural approach is a key part of the intervention for both populations. However, there have been no attempts to apply the widely used adult model of OCD of Salkovskis to children (Shafran, 2001) and only limited applications of other cognitive models to adolescents (e.g. Shafran & Somers, 1997). There are also clear differences in the cognitive components of the cognitive behaviour therapies used with and younger children. The adult model provides a clear theoretical rationale for the use of cognitive interventions. In the child neurobehavioural model the link between cognitive theory and practice is unclear and there is no consensus on what any cognitive component of treatment might be (Shafran, 1998). This situation makes it difficult to compare the theory of OCD in children and adults, which is one aim of this essay. However, an examination of the developmental literature on OCD may offer some insight into how well the adult model could be applied to children.

It has been reported that the mean age of onset of childhood OCD is 10.3 years (Shafran, 2001). However, ritualistic and compulsive behaviours are common in younger children, in both their play and during times of anxiety. These behaviours appear to be most intense and frequent amongst 2-4 year olds. They then reduce with age, before disappearing at around 8 years old (Evans et al., 1997). These behaviours are distinguishable from obsessive-compulsive behaviours in that they do not impair functioning or cause distress (Rapoport & Inoff-Germain, 2000). Bolton (1996) looked at the similarities between “magical thinking” in children and the thoughts and behaviours associated with OCD. Magical thinking was described as a stage of reasoning during which the child overestimates their influence over
external events. It was suggested that if an event was anxiety provoking for the child, magical thinking could motivate them to act to reduce that anxiety. As already reported, childhood behaviour at times of anxiety may be ritualistic. The child could therefore come to believe that their ritualistic behaviours “magically” influence external events. This therefore offers a developmental account of how obsessive-compulsive behaviours may arise. The onset of OCD could be caused by a critical incident either reactivating pre-rational coping strategies or raising pre-existing developmental obsessive-compulsive behaviours to the clinical level.

Differences in cognitive ability due to developmental stage also need to be considered if adult cognitive models are to be applied to children. The cognitive processes associated with the adult model of OCD (e.g. assessing the probability of harm and responsibility for it) require the ability to anticipate future outcomes and have a developed concept of the self. Significant changes in these abilities occur around the age of 8 years old (Henin & Kendall, 1997). Young children are also less likely to describe their symptoms as unrealistic or excessive and are more present orientated (Piacentini, 1999). They may therefore be less likely to engage in anxiety provoking therapy that aims to produce longer-term, future changes. Less developed language skills mean that the relationship between obsessions and compulsions is much less clear in children than adults, as children are less able to articulate what their specific fears are (Piacentini, 1999). This could complicate the construction of an accurate fear hierarchy and effective exposure exercises, which would impact upon the therapeutic process.

In summary, the lack of research on OCD in children makes it difficult to draw any firm conclusion on whether OCD in children and adults is fundamentally different. Clearer theories on the development and maintenance of childhood OCD and more controlled trials of treatments for it are needed. The developmental literature highlights some potential difficulties for the application of the adult cognitive model to children. However, developmental cognitive models may also allow further expansion and refinement of the model. For example, the developmental account of Bolton (1996) is not incompatible with Salkovskis’ model of OCD. It could explain how the individual develops what appear to be less logical (or more magical) compulsive behaviours (e.g. touching a certain number of times, mental counting) and an inflated perception of their responsibility over events. Better integration of the theory of OCD in adult and child populations is therefore needed in future research (Shafran, 1998).
Panic Disorder in Adults

Those who suffer from panic disorder experience recurrent and unexpected panic attacks (American Psychiatric Association, 1994). A panic attack involves the sudden onset of a period of intense fear. It includes four or more of the following symptoms, which develop abruptly and peak within ten minutes: palpitations; sweating; trembling; shortness of breath; feeling of choking; chest pain; nausea; dizziness; derealisation; fear of losing control or going crazy; fear of dying; numbness or tingling; chills or hot flushes. The attacks are often accompanied by a sense of impending danger and the urge to escape (American Psychiatric Association, 1994). The individual is afraid of both what the symptoms of the attack mean (e.g. I am having a heart attack, I am going crazy) and the possibility of having further attacks. In clinical practice, these panic attacks need to be distinguished from raised anxiety levels associated with other anxiety disorders that may be described as panic through self-report (Dummit & Klein, 1994).

Prevalence studies have estimated that panic disorder has a lifetime prevalence of 3.5% and a twelve-month prevalence of 2.3% (Kessler et al., 1994). It is therefore a relatively common psychiatric disorder seen in adult mental health services (Taylor, 2000). Panic disorder is currently treated by the use of medication, relaxation, behaviour therapy and cognitive-behaviour therapy (American Psychiatric Association, 1998; Clark, 1997). The cognitive model of panic of Clark (e.g. 1989, 1997) has been widely researched and used in clinical practice (Ollendick, 1998).

Cognitive approaches to emotional disorders argue that it is the way events are perceived that causes the individual distress rather than events themselves. Clark (e.g. 1989, 1997) has proposed that panic attacks occur after the individual has interpreted a stimulus, either external (e.g. a particular situation) or internal (e.g. a thought), as signifying a threat. This raises the individual's anxiety levels, which involves a number of physiological changes (e.g. increased heart and breathing rates; Beck & Emery, 1985). The individual misinterprets these somatic sensations as an indication that a catastrophic event, involving serious bodily or mental harm, is about to occur. This misperception leads to a further increase in anxiety and related symptoms. Thus, a cycle of catastrophic thoughts and increased bodily sensations is set up.

Clark suggested that after an individual has catastrophically misinterpreted bodily sensations they might become hypervigilant for future panic attacks. This would involve scanning their
body for further physiological signs of danger. The individual is therefore more likely to notice bodily sensations they would otherwise have missed, which are then perceived as confirmation that the individual is at risk of some physical or mental catastrophe. This maintains raised anxiety levels and increases the likelihood of further panic attacks. Another maintaining factor for panic disorder is the use of "safety behaviours" (e.g. Clark, 1999). The individual engages in these behaviours in an attempt to reduce the probability of their feared catastrophe occurring. However, the behaviours also prevent the individual from learning that their feared event will not happen.

Cognitive-behaviour therapy for panic disorder aims to reduce the individual's anxiety by teaching them how to identify, challenge and modify their catastrophic thoughts and beliefs (e.g. Clark, 1989). The therapist and patient work together to test out whether the catastrophic hypothesis of the individual (e.g. I will die) or an alternative hypothesis about the panic disorder is correct. The individual is given information about anxiety and its symptoms, relaxation techniques, distraction techniques and how to challenge their negative perceptions. Behavioural experiments are also devised to help modify the catastrophic interpretations of bodily sensations. One experiment commonly used during therapy is hyperventilation. It is hypothesised that the individual's interpretation of the symptoms of panic attacks (e.g. I will die) is mistaken and instead the symptoms are due to hyperventilation. The therapist and patient then hyperventilate together and discussion of the sensations that arise then follows. Breathing retraining can help the individual control their panic symptoms. Other parts of the intervention aim to stop avoidance and the use of safety behaviours through further discussion and behavioural experiments. This helps the individual challenge their belief about the level of threat they are under.

Empirical evidence exists to support this cognitive theory. Ehlers and Breuer (1992) demonstrated that those with panic disorder had greater awareness of bodily sensations (heartbeat) than those with simple phobias, those with infrequent panic attacks and a control group. The hypothesis that people with panic disorder are more likely to catastrophically interpret bodily sensations has also been supported by studies (e.g. Ehlers, Margraf, Roth, Taylor & Birbaumer, 1988; McNally & Foa, 1987). Other research has indicated that dropping safety behaviours can lead to a decrease in catastrophic beliefs and anxiety (Salkovskis, Clark, Hackmann, Wells & Gelder, 1999). Clark (1999) reviewed the outcome of seven controlled treatment trials of cognitive therapy for panic disorder in adults. It was reported that at the end of treatment an average of 84% of the samples were panic-free. It was also reported that treatment gains were maintained at one and two year follow-up.
Panic Disorder in Children

The literature on panic disorder in children and adolescents is much less developed than the literature on panic disorder in adults (American Psychiatric Association, 1998). There has been considerable debate over whether younger children can even experience panic disorder (e.g. Moreau & Follett, 1993). Nelles and Barlow (1988) argued for full panic disorder an individual needs to be able to experience the physiological symptoms associated with the disorder and also cognitively associate with them the process of dying, going crazy or losing crazy. The authors felt that younger children’s associate physiological sensations with external events (e.g. My heart beats faster whenever I take a test), rather than some internal causality (e.g. I am dying). This ability to attribute sensations to internal events develops further in adolescence. Therefore, although younger children may experience the physical sensations of panic disorder, they cannot catastrophise and cannot therefore have full blown panic disorder. Adolescents are more likely to experience this. This is consistent with reports that the age of onset of panic disorder is typically early to middle adulthood (Masi, Favilla, Mucci, & Millepiedi, 2000).

However, there are retrospective reports from adults with panic disorder that their panic attacks started at a younger age (Ollendick, 1998). A review of a number of studies that had investigated whether panic disorder existed in younger people concluded that the data supported the presence of both cognitive and physiological symptoms in the population (Ollendick, Mattis & King, 1993). A research study has explored the cognitive responses to somatic symptoms of panic in 8, 11 and 14 year olds (Mattis & Ollendick, 1997). It was found that children in all the age groups were equally likely to interpret somatic symptoms as an indication that they were dying, losing control or going crazy. Other research concluded that there was little difference between adolescents and younger children with panic disorder. Although the younger children reported fewer cognitive symptoms, the differences between the two groups were not statistically significant (Masi, Favilla, Mucci, & Millepiedi, 2000) and it appears at least some younger children have the cognitively ability to catastrophise (Ollendick, 1998).

Findings such as those reported here have led many researchers to conclude that children and adolescents do experience panic attacks and panic disorder (Ollendick, 1998; Kearney, Albano, Eisen, Allan & Barlow, 1997; Moreau & Follett, 1993). Further, the symptoms experienced by younger people appear to be similar to those experienced by adults (Moreau & Follet, 1993). The most common sensations experienced by younger children are palpitations,
shortness of breath, seating and weakness. In adolescence new symptoms arise, such as chest pain, flushes, trembling, headaches and vertigo (Masi, Favilla, Mucci, & Millepiedi, 2000). It is not known whether there is a lower age at which panic can occur, but some reports have included children as young as 5 years old (Taylor, 2000).

A review of the few prevalence studies that have occurred estimated that panic disorder occurs in about 1% of adolescents (Kearney, Albano, Eisen, Allan & Barlow, 1997). However, there is a need for considerably more empirical work in this area to support this figure. There is also no data on the prevalence of panic disorder in younger children (Ollendick, Mattis & King, 1993). Some have reported that younger children do not spontaneously talk about their panic symptoms. This may lead to those with panic disorder being offered medical rather than psychiatric support (Moreau & Follett, 1993). There are therefore probably many children with panic disorder who do not currently come to the attention of mental health services (Masi, Favilla, Mucci, & Millepiedi, 2000).

Literature on the treatment of panic disorder in younger people consists mainly of case studies and small, uncontrolled trials in which the majority of the subjects are adolescents (Taylor, 2000). One study outlined a protocol for the use of cognitive-behavioural therapy to treat adolescents and reported positive outcomes for four cases (Ollendick, 1995). However, in general there is little support for the efficacy of any treatment for panic disorder in children and adolescents (American Psychiatric Association, 1998).

The discussion on whether panic disorder exists in younger children has arisen as a result of attempts to apply the cognitive model of panic used with adults. Further research is needed to explore if this is appropriate. The developmental literature may provide some insight into how well the model can be applied.

One debate amongst those investigating the development of panic disorder has concerned the relationship between panic disorder and separation anxiety. Broadly, separation anxiety is developmentally inappropriate anxiety related to separation from home or attachment figures (American Psychiatric Association, 1994). It has been suggested that there is a high correlation between those who have separation anxiety in children and the development of panic disorder in adults (Moreau & Follett, 1993). This has led some to suggest that separation anxiety should be re-formulated as a child version of adult panic disorder (Moreau & Follett, 1993). However, the association between separation anxiety and panic disorder is an inconsistent finding (American Psychiatric Association, 1998). It may be that early
separation anxiety is a risk factor for the development of panic disorder (Masi, Favilla, Mucci, & Millepiedi, 2000) or is one of many causal pathways to the development of panic disorder (Ollendick, 1998). Further research is needed to clarify whether there is a link between the two disorders and what the nature of this link might be.

Some researchers have also speculated upon developmental models for panic disorder (e.g. Ollendick, 1998; Kearney, Albano, Eisen, Allan & Barlow, 1997). Kearney and colleagues (1997) proposed that many children are psychological and biologically vulnerable to the development of panic disorder. Biological vulnerability is due to a predisposition to experience occasional hyperarousal (e.g. hyperventilation). Psychological vulnerability is due to anxiety sensitivity. This is the tendency to respond fearfully to anxiety symptoms. Before the age of 9, most children are not able to conceptualise bodily sensations as “dangerous”. Therefore, panic rarely occurs in very young children. However, as children grow and become more aware of death and serious injury, vulnerable individuals may catastrophise physical symptoms and develop an anxiety disorder. The authors provide the example of an adolescent with hyperarousal and anxiety sensitivity. He/she may react to shortness of breath with cognitive beliefs about dying from asphyxiation, thus triggering a panic attack. Stressful life events may mediate some of the child’s beliefs and thus also influence the occurrence of a panic attack. Again, there has been limited research in this area. However, models such as this could provide hypotheses for future empirical work.

With regard to developmental considerations for treatment using the cognitive model, the debate on whether children can catastrophise bodily sensations has already been outlined. Another factor that needs to be addressed is the finding that younger children are often not cognitively able to make connections between their panic symptoms and avoidance behaviour (Moreau & Follet, 1993). Any cognitive-behavioural treatments and explanations of panic disorder therefore need to be appropriate for the child’s developmental level. For example, catastrophic interpretations could be understood as false alarms (Taylor, 2000).

In summary, the literature on panic disorder in children and adolescents is slowly developing. Research is starting to move from questions about whether younger people have panic disorder to questions on the nature of this panic disorder (Kearney, Albano, Eisen, Allan & Barlow, 1997). Despite these advances, the current knowledge about panic disorder in children and adolescents is very limited. It is therefore not possible to conclude whether panic disorder in adults and children is fundamentally different. It does appear that panic is rare/non-existent in children under 8. This may imply that a level of developmental maturity
is necessary for the disorder to occur, which could support the catastrophic thoughts hypothesis of the adult cognitive model. However, further considerably more research is needed in all areas relating to panic disorder in children and adolescents.

Conclusion

This essay aimed to explore whether anxiety disorders in children and adults are fundamentally different by discussing the research on the theory and treatment of OCD and panic disorder. However, it was not possible to draw any firm conclusions from the current literature. The main reason for this has been that there is very little link between research on the disorders in the two populations. Adult cognitive models are relatively well developed and treatment follows directly from these models. However, little attention is paid to the early genesis of these disorders, with reference to childhood usually limited to a small “early life experiences” box in the models. Research on anxiety disorders in children is very limited, particularly in relation to panic disorder. In OCD, the use of cognitive-behavioural treatments is described, but the basis of these and what they aim to achieve are not clearly linked to a model.

Future research could therefore aim to take a life-cycle perspective of anxiety disorders. This could improve psychological treatments and advance theoretical models for the disorders across the age range. However, for this to occur the amount of research on anxiety disorders in children needs to increase considerably.
References


“Dementia Cannot Be Cured. It Takes its Course”. Critically Evaluate
With a Discussion of Known Theories of Causes
and Treatment Approaches

Completed in Year 2
Introduction

The National Service Framework for Older Adults (NSF; Department of Health, 2001) reports that approximately 600,000 people in the UK have dementia. Only 17,000 of these people are under the age of 65. Dementia is therefore particularly associated with the later stages of life. Woods (1999a) reviewed the research literature and reported a consensus that the prevalence of dementia doubles for each increase in age of 5.1 years over 60. This means that about 5% of the population over 65 years old have a dementia, but this rises to 20% of the population over 80 years old. As the UK has an aging population, this has particular relevance for the NHS (Department of Health, 2001). The NSF forecasts that the number of people with dementia in the UK will increase to 840,000 by 2026 and 1.2 million by 2051.

The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV; American Psychiatric Association, 1994) outlines five broad categories of dementia, differentiated by theories of aetiology: Dementia of the Alzheimer’s Type; Vascular Dementia; Dementia Due to Other General Medical Conditions (e.g. HIV, Parkinson’s disease, Huntingdon’s disease); Substance-Induced Persisting Dementia; Dementia Due to Multiple Etiologies. Some characteristics are common to all the dementias in DSM-IV (see table 1).

<table>
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<th>The development of multiple cognitive deficits manifested by both:</th>
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<tr>
<td>A</td>
<td>1) memory impairment (impaired ability to learn new information or to recall previously learned information). 2) one or more of the following cognitive disturbances: (a) aphasia (language disturbance); (b) apraxia (impaired ability to carry out motor activities despite intact motor function); (c) agnosia (failure to recognise or identify objects despite intact sensory function); (d) disturbance in executive functioning (i.e. planning, organising, sequencing, abstracting).</td>
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<td>B</td>
<td>The cognitive deficits in criteria A1 and A2 each cause significant impairment in social or occupational functioning and represent a significant decline from a previous level of functioning.</td>
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Table 1: Criteria common to the dementias defined in DSM-IV

These characteristics highlight that essentially dementia involves a decline in intellectual functioning (Miller & Morris, 1993). Although DSM-IV makes no assumptions about
prognosis, traditionally this impairment is seen as progressive (McLoughlin & Levy, 1996). Midence and Cimliffe (1996) have offered an outline of how a dementia can proceed, although there is wide variation between individuals. The global cognitive decline continues, affecting the person's functioning, mood, personality and behaviour. The person's ability to interact with the world around them gradually reduces and they become increasingly disorientated to time, place and person. He or she slowly loses the ability to complete activities of daily living (e.g. washing, dressing, eating) and eventually needs full supervision and then full care. During the final stages of dementia there is total intellectual, motor and behavioural loss and the person enters a vegetative state. Death usually occurs as a result of pneumonia or other unspecific causes.

The majority of dementia sufferers live in the community and are cared for by relatives (Dunkin & Anderson-Hanley, 1998). Huge individual changes in the dementia sufferer, such as those described above, will obviously affect these carers. They suffer an emotional reaction to the changes in their relationship with the person with dementia in addition to having to manage the increasingly stressful practical considerations (Miller & Morris, 1993). This contributes to the fact that many people are admitted to care home when their dementia becomes severe, which has increased cost implications for service providers (Alloul et al., 1998). These factors help demonstrate that dementia is a wide-ranging condition that incorporates biological, psychological and social aspects.

This essay is specifically concerned with the proposition: “Dementia cannot be cured. It takes its course”. The Concise English Dictionary (Collins, 2001) defines “to cure” as “to get rid of an ailment or problem; heal”. In relation to illness, “course” is defined as “regular procedure”. This essay will therefore evaluate whether dementia can be stopped or reversed (i.e. cured) and whether dementia inevitably follows a regular procedure. It will achieve this by discussing theories about the cause of dementia, as well as the medical and psychological treatments currently used. It is not possible in the space available here to review this literature for all the different types of dementia. Instead, Dementia of the Alzheimer's Type will be discussed, as this is the most common form (Department of Health, 2001). In conclusion, the implications of the discussion for the title proposition will be evaluated and future directions for clinical practice and research suggested.
Dementia of the Alzheimer's Type (DAT)

Features of DAT

DAT is so-called because at present it can only be firmly diagnosed by post-mortem brain examination. Any diagnosis whilst the person is alive can therefore only ever be a provisional hypothesis (Lezak, 1995). DAT is the most prevalent form of dementia, causing up to 60% of dementia cases (Department of Health, 2001). As well as the general characteristics of dementia outlined in table 1, DSM-IV also describes features specific to DAT (table 2).

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<tr>
<td><strong>C</strong></td>
<td>The course is characterised by gradual onset and continuing cognitive decline.</td>
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<td><strong>D</strong></td>
<td>The cognitive deficits in criteria A1 and A2 are not due to any of the following:</td>
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<tr>
<td></td>
<td>1) other central nervous system conditions that cause progressive deficits in memory and cognition (e.g. cerebrovascular disease, Parkinson's disease, Huntingdon's disease).</td>
</tr>
<tr>
<td></td>
<td>2) systemic conditions that are known to cause dementia (e.g. hypothyroidism, vitamin B12 or folic acid deficiency, niacin deficiency, hypercalcemia, neurosyphilis).</td>
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<td></td>
<td>3) substance-induced conditions.</td>
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<tr>
<td><strong>E</strong></td>
<td>The deficits do not occur exclusively in the course of a delirium</td>
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<tr>
<td><strong>F</strong></td>
<td>The disturbance is not better accounted for by another Axis 1 disorder (e.g. Major Depressive Disorder, Schizophrenia)</td>
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Table 2: DSM-IV criteria for DAT

Bouchard and Rosser (1996) have outlined how the cognitive decline in DAT might progress. In the early stages, memory difficulties are the most prominent feature. The individual has poor memory for recent events – he or she could forget the content of recent discussions, forget to pass on messages and may become disorientated in unfamiliar surroundings. The person may have difficulties with word finding and following some conversations.

As the dementia progresses, memory impairments become more pronounced. The person is unable to work, needs help travelling and may begin to forget familiar people. Disorientation and circumlocution (talking around a word that cannot be brought to mind due to word-finding difficulties) increase, whilst verbal comprehension, reading and calculation skills decrease. Motor slowing also becomes noticeable. Later still the person forgets close relatives and personal information. Both expressive and receptive language skills continue to
deteriorate. Participation in the wider social world and activities of daily living decrease, and the person needs increasing amounts of support and supervision. In the final stages of dementia, the person is seemingly oblivious to their environment. He or she needs full care and eventually becomes bedridden. The person is largely uncommunicative, either producing incomprehensible utterances or being completely mute. People with DAT usually die as a result of pneumonia, urinary tract infection or age-related disease such as heart disease or cancer (Cummings, 1994; cited in Tremont & Mittenberg, 1996). As DAT starts gradually and its early affects can be confused with the normal aging process (McLoughlin & Levy, 1996), it is difficult to estimate how long DAT takes to progress (Lezak, 1995). However, DSM-IV suggests that the average duration from onset of symptoms to death is 8-10 years.

In a series of papers, Burns, Jacoby and Levy (1990a, b, c, d) examined non-cognitive phenomena in 178 people who had been diagnosed with DAT according to strict criteria. To minimise bias they selected a sample that was epidemiologically representative of their inner city catchment area. The assessment was completed using standardised procedures, examination of medical records and interviews with the client, relatives and nursing staff. They found that 16% of their sample had had delusions since the onset of the DAT. Disorders of perception also appeared commonly, with 13% experiencing visual hallucinations, 10% auditory hallucinations and 30% misidentification syndrome. Features of depression were also present, with 63% of the sample reporting at least some depressive symptomology. With regard to behaviour, aggression and wandering were each identified in 20% of the sample. Other behavioural difficulties included binge-eating, sexual disinhibition and incontinence.

Neuropathology in DAT

The neuropathological features most commonly associated with DAT are neuronal loss, brain atrophy, neurofibrillary tangles (NFTs) and senile plaques (Kitwood, 1997). These features are also found in the brains of many non-dementing older adults (McLoughlin & Levy, 1996). However, in people with DAT they occur to a greater extent. This has led some to hypothesise that DAT represents an acceleration of the normal ageing process (Tremont & Mittenberg, 1996).

Neuronal loss occurs throughout the brains of people with DAT, but particularly in the cerebral cortex and hippocampus (Kalat, 1988). People with DAT therefore have fewer
synaptic connections, which disrupts brain functioning. The neuronal loss eventually leads to significant changes in brain structure. The brains of people with DAT have larger sulci, larger ventricles and reduced overall mass when compared to age-matched controls (Lezak, 1995). However, the degree of overlap between these two groups is so large that this statistic is not diagnostically helpful (Blass & Poirier, 1996).

NFTs and senile plaques have been considered hallmark features of DAT (Blass & Poirier, 1996). Lovestone (1995) has described NFTs and senile plaques in some detail. To summarise, NFTs are tangled bundles of fine fibres that are principally composed of abnormal tau protein. They appear within the cell bodies of neurons and so are likely to contribute to the disruption of neuronal functioning. Senile plaques are large extracellular structures composed of a core of amyloid protein. Their presence is also thought to prevent normal brain functioning.

Theories of the Cause DAT

The standard model used in current dementia research and clinical practice is neurobiological (Rosenberg, 2000). Kitwood (1997) expressed this model in the form of a diagram (see figure 1).

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Factor or Factors X ───► Neuropathic change ───► Dementia
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Figure 1: The standard model of dementia.

The model proposes that some factor ("X") causes physiological changes in the brain. These physiological changes, in turn, cause the changes in cognition and behaviour associated with DAT. This is consistent with the title proposition. According to the model, if dementia is to be cured, the neuropathic changes have to be stopped or reversed. Further, the behavioural and cognitive changes associated with the dementia will follow a regular procedure unless the neuropathology is altered. The "X Factor(s)" (the cause of DAT) is (are) not known at present (Tremont & Mittenberg, 1996). However, both medical and psychological treatments are currently used. If these treatments change either the neuropathology or presenting features of DAT, this will be evidence opposing both the standard model of dementia and the
title proposition. The remainder of this essay will therefore discuss the effectiveness of these treatments for people with DAT.

Medical Treatments for DAT

Among the first neurons to degenerate in the brains of people with DAT are those that release the neurotransmitter acetylcholine. This neurotransmitter is associated with memory function, so some have hypothesised that this is the cause of the memory impairment seen in DAT (Carlson, 1992). This “cholinergic hypothesis” has led to attempts to increase the levels of acetylcholine through pharmacological interventions.

At present, the National Institute for Clinical Excellence (NICE; 2001) recommends the use of three drugs with people who have DAT (Donepezil, Rivastigmine and Galantamine). These drugs all inhibit a brain enzyme called acetylcholinesterase. In normal brain activity, this enzyme breaks down acetylcholine once it has performed its synaptic function. These drugs therefore prolong the effects of acetylcholine by inhibiting the enzyme that breaks it down. From a review of the evidence, NICE report that using these drugs does stop cognitive decline and can produce small cognitive improvements in some people with DAT. However, as the disease progresses, the levels of acetylcholine continue to fall, eventually going below pre-treatment levels. At this time, continuation of the treatment is not considered beneficial. Therefore, the drugs can delay the onset of more severe impairments, but the eventual outcome of DAT remains the same.

Bullock (2001, 2002) has reviewed non-cholinergic drug therapies for DAT. These include the use of vitamin E, oestrogen, anti-inflammatory drugs and a “vaccination” for the amyloid plaques. However, these treatments are still being researched and developed, so their effectiveness is unclear at present.

Psychological Treatments for DAT

A number of psychological interventions are applied to people who have DAT. Five that are more commonly used are discussed below. These are: Reality Orientation, Validation Therapy, Reminiscence Therapy, Memory Management and Behavioural Interventions.
Reality Orientation

Reality Orientation (RO) was originally developed in the 1950s to reduce confusion in any institutionalised individuals, no matter what the cause of the confusion might be (Miller & Morris, 1993). RO is now the most common psychological intervention used with people who have dementia (Morton & Bleatham, 1988).

There are two forms that RO takes – Classroom RO and 24-hour RO (Midence & Cunliffe, 1996). Classroom RO involves small groups of people with dementia and care staff meeting regularly for half hour sessions. Staff encourage people to interact with others and provide orientating cues and information. This includes having a clearly labelled environment, including a whiteboard as a focus for current information, such as the topic under discussion. Activities and materials are provided to provide cognitive stimulation and promote contact with others.

Twenty-four hour RO extends this orientation program throughout the whole day (Miller & Morris, 1993). The whole environment of the person with dementia is restructured to facilitate orientation. Care staff consistently insist (kindly, but firmly) that the person with dementia becomes involved in self-care tasks and conversation to the best of his or her abilities. Care staff also provide basic orientating information (e.g. time, name) to the person with dementia in all their interactions and encourage the person to become involved in their environment (e.g. by commenting on what is happening, reinforcing interest). This is sometimes adjusted so that the orientating information is only provided in response to requests, rather than on every occasion (Woods, 1999b).

Kasl-Godley & Gatz (2000) reviewed the empirical evidence on Classroom RO with people with dementia. In the seven studies they reviewed (five from in-patient settings and two from day hospital settings), people in the RO groups all improved on some outcome measures when compared to controls. However, the nature of these improvements highlights what is the main difficulty with the RO approach. People in the RO groups tended to improve on measures of cognition, particularly orientation. However, there was little (if any) effect on behavioural functioning and the improvements in orientation did not tend to continue once the RO programs were stopped. Morton and Bleathman (1988) discuss these problems in their paper “Does it matter whether it’s Tuesday or Friday?”. They point out that RO can be frustrating for both care staff and the people with dementia. The frequent corrections that the
approach requires provide a constant reminder to everyone that the person with dementia does not know where he or she is or what day it is. This can damage staff-client relationships and increase the person with dementia's distress and sense of isolation from the world.

RO has, therefore, been the subject of criticism. However, it does appear that it can produce some positive changes for the person with dementia, largely in orientation. It has also been suggested that non-specific treatment effects, such as an increased amount of communication between clients and staff, are positive outcomes of RO (Kasl-Godley & Gatz, 2000). This suggests that RO does have a role to play in the treatment of people with dementia. However, it may be most useful when it is altered to meet the individual needs of people with DAT (Miller & Morris, 1993). Further research on such adaptations to the RO approach would provide a useful framework for future clinical applications.

*Validation Therapy*

Naomi Feil, a social worker in the US, grew up in an “old peoples” home that was run by her parents. She saw RO in practice and found the emphasis on “reality” confrontational and unhelpful (her criticisms are outlined above and in Morton & Bleatham, 1988). She therefore formulated an alternative approach – Validation Therapy (VT). VT shifts the focus from the factual content of speech on to the experience of the person with dementia. Validation therapists respond to what they think is the underlying emotional meaning of speech and behaviour. Techniques used include verbal and non-verbal (e.g. touch, eye contact, tone) communication, music and reminiscence. The aim is to validate the person’s subjective experience, thus demonstrating respect for them as an individual. VT can be used both in structured settings (either group or individual) and as part of routine care (Midence & Cunliffe, 1996).

The theory behind VT emphasises what has happened previously in the life of the person with dementia. It is thought that through their communication they are returning to the past to resolve unfinished conflicts before the end of their life. People with dementia progress through four stages (malorientation, time confusion, repetitive motion and vegetation), showing increased physical deterioration and withdrawal from the world. Painful feelings from the past that are expressed and validated reduce in strength. This helps restore dignity and prevent the person deteriorating into vegetation (Kasl-Godley & Gatz, 2000).
Research on VT has been very limited, although there are anecdotal reports of positive outcomes from Naomi Feil (e.g. Feil, 1993; cited in Woods, 1999b). Morton & Bleatham, (1991) have carried out a pilot study on the effectiveness of a weekly VT group. Of the five group members it was possible to evaluate outcome for only three (of the others, one died during the experimental period and one attended infrequently). Two of these subjects showed an increase in both the length of interactions and the number of interactions initiated by themselves. Further, these findings started to return to baseline when a reminiscence group replaced the VT group. For the third subject, the opposite occurred – that is, interactions increased during the reminiscence group and decreased during the VT group.

Although this research offers the possibility that VT may be a useful intervention, further studies are obviously needed. In this author’s opinion, VT may be more usefully perceived as a service philosophy, as it promotes respect for and interaction with people who have dementia. Such factors may well account for the changes that Feil and Morton and Bleatham have attributed to VT (Woods, 1999b).

Reminiscence Therapy

Reminiscence Therapy (RT) was originally developed for use with older people without dementia, in order to provide them with an opportunity to review and reconstruct events in their lives (Midence & Cunliffe, 1996). It has been proposed that this is a major psychological task of later life (Erikson, 1963). However, people with dementia find it difficult to reflect on their whole life due to their cognitive deficits (e.g. memory). RT for this group is therefore aimed more at providing cognitive stimulation and a framework for interaction (Woods, 1999b). It occurs in a relaxed and positive atmosphere, with props (e.g. photographs, newspapers) used to stimulate memories.

One empirical study compared the effects of group RT with other group activities (Head, Portnoy & Woods, 1990). Two day centre settings were used, one institutional and one community based. In the institutional setting there was little baseline interaction and the group members were more cognitively impaired. The results showed that the RT group in this setting showed an increase in interaction within the group significantly higher than the control. However, there was no clear difference between the two groups in the community day centre. This was thought to reflect the fact that the alternative activities provided in that
day centre were more stimulating. There was therefore more interaction at baseline and consequently less room for improvement.

Thornton and Brotchie (1987) reviewed the literature and concluded that the therapeutic effects of reminiscence in people without dementia had not been demonstrated, although it did have beneficial effects on staff knowledge about their clients. However, a more recent review concluded that in people with dementia RT can lead to improvements in social and psychological functioning, such as better relationships with care staff and a decrease in behavioural problems (Kasl-Godley & Gatz, 2000).

RT appears to have beneficial outcomes for people with dementia, particularly in terms of offering a framework for interaction. An additional factor supporting its use is that many of the people who get involved in it (both carers and dementia-sufferers) find it an enjoyable experience (Miller & Morris, 1993). Further outcome research is still needed. This could include specifying what type of RT is most useful and what factors contribute to any improvement (Woods, 1999b).

Memory Management

As outlined earlier, memory decline is a key feature of dementia. However, research has shown that people with dementia can learn new information. For example, one study repeatedly assessed the performance of people with DAT on paired associate learning tasks over six months (Liddle, Volans, Hemsley & Levy, 1986). They found their subjects were able to retain information at a level comparable to baseline. Overall, evidence suggests that after the first 10 minutes, people with dementia forget at the same rate as others (Woods, 1999b). Procedural and implicit memory, which are memory systems with no cognitive reference, also appear to be preserved (Miller & Morris, 1993). Some have therefore tried to support the cognitive performance of people with dementia by using these relative memory strengths.

One study reported on the effective use of procedural memory to help people with DAT complete daily living activities faster than a control group (Zanetti, Magni, Binetti, Bianchetti & Trabucchi, 1994). Another study reported on the application of errorless learning techniques to help a 72-year-old man with DAT learn the names of photographs of eleven people in his social club (Clare, Wilson, Breen & Hodges, 1999). Errorless learning involves
preventing (as far as possible) a person from making mistakes when they are in the process of learning something. It has been used successfully with people who have memory impairments (Wilson, 2000).

In the case study above (Clare, Wilson, Breen & Hodges, 1999), four strategies were used to minimise errors in the learning process. Firstly, the subject was repeatedly instructed not to make guesses but instead say he did not know. Secondly, the subject was supported to create a mnemonic cue for each name from the appropriate picture. Thirdly, initial learning used a vanishing cues method. This involved prompting the subject to recall the name with a step-by-step reduction in the number of letters presented (e.g. CAROLIN___; CAROLI__; CAROL____ etc.). Finally, retention was encouraged using an expanded rehearsal method. This involves learning one item at a time, starting with a short initial retrieval period. The time before the next retrieval trial depends upon whether the item was recalled correctly. If it was, the time is doubled, if not it is halved. The item therefore becomes fully registered, so will be subject to a normal rate of forgetting, as outlined above. In this study, correct naming rose from 22% at baseline to 98% after intervention. The learning also generalised well from photos to real faces and was maintained at 9 months follow up.

Strategies aimed at supporting the memory of people with DAT can therefore result in behavioural and functional change. Errorless learning in particular may be a very useful technique. These approaches need to be applied more extensively to larger samples of people and a wider range of learning tasks. Future research should investigate such possibilities.

**Behavioural Interventions**

Changes in behaviour are an important part of dementia and have a big influence on carer stress (e.g. Dunkin & Anderson-Hanley, 1998). Behavioural interventions are based upon the concept that behaviour can be explained by certain learning principles. When applying behavioural management strategies to people with dementia, it is assumed the same learning principles are involved (Kasl-Godley & Gatz, 2000). Classical and operant conditioning are the two core learning theories used in behavioural approaches. Both types of learning have been shown in people with dementia (Burgess, Wearden, Cox & Ray, 1992; Morris & Miller, 1993).
Fisher and Carstensen (1990) reviewed the research on the behavioural management of people with dementia and reported that behavioural interventions were moderately effective. However, there have been few controlled studies in this area (Woods, 1999b). One such controlled trial evaluated the effectiveness of a behaviour management training program for family carers of people with dementia and aggressive behaviour (Gormley, Lyons & Howard, 2001). The program involved education about dementia and behavioural principles and support in analysing behaviour and constructing behavioural interventions. The authors reported a trend towards a reduction in the behaviour management group compared to the control group and concluded that this added to the evidence base for the effectiveness of behavioural interventions. Although the training program was brief and the dementia subjects were in the moderate to severe stages of the disease (both of which could have influenced the outcome of the study), it is important to note that the difference between the two groups was not statistically significant (p=0.071).

The evidence suggests that people with DAT learn behaviours according to the same principles as the general population. Further, studies investigating the application of the behavioural model suggest that it can produce changes in the behaviour of people with DAT. However, again this evidence is still inconclusive. There is a need for further research, in particular more controlled trials.

Summary and Conclusions

In this essay the effects of DAT (biological, psychological and social) have been outlined, along with the model of dementia currently used in most clinical research and practice (figure 1). This model implies that some factor causes the neuropathology associated with DAT, which in turn causes the symptoms of the dementia. Therefore, only removing or stopping the neuropathology can cure DAT or alter the changes it brings on the individual.

At present, no intervention can “get rid of” or “heal” DAT. Medical treatments aim to mask some of the neuropathological changes by increasing the levels of the neurotransmitter acetylcholine in the brain. This provides some benefits, but as the pathology worsens these benefits reduce. This supports both the standard model of dementia and the first part of the title proposition. Altering the effects of the pathology alters the presentation of the dementia. However, this is only temporary and at present DAT cannot be cured.
Considerably more research is needed about all of the psychological treatments discussed here. However, it does appear that the "regular procedure" of DAT can be altered to some degree. Memory management and RO have evidence demonstrating positive changes in people with DAT. Behavioural interventions, RT and VT also show some promise in promoting change. However, in this author’s opinion these latter two approaches may be best conceptualised as frameworks for improving the standard of care of people with dementia. They can encourage respect for people with DAT as individuals and promote interaction with care staff.

The second part of the title proposition is therefore not supported by this discussion. People with DAT are not on a completely unchangeable path and some new learning and positive changes are possible (although as DAT cannot be cured, progressive decline cannot in itself be stopped). The fact that psychological interventions that do not affect brain pathology can alter the individual's experience of DAT also calls into question the standard model of dementia. This has implications for research and clinical practice. It suggests an alternative way of understanding DAT, which can account for psychological and social factors as well as biological ones, may be more useful. Kitwood (1997) has criticised the standard model of dementia as being too reductionist and an oversimplification. He has proposed an alternative conceptualisation of dementia (figure 2).

\[
\Psi' \equiv b \\
(B^d, B_p)
\]

where \( \Psi = \) psychological experience

\( b = \) brain activity

\( B^d = \) brain development

\( B_p = \) brain pathology

[Any psychological event or state is also a brain event or state, ‘carried’ by a brain whose structure has been determined by both developmental and pathological factors]

Figure 2: One alternative to the standard model of dementia (from Kitwood, 1997)

This model acknowledges that a psychological event necessarily involves organic brain changes (e.g. in the formation of a memory). This occurs in the context of a brain whose development has been influenced by an individual’s genes and life experiences. This model therefore offers a framework for investigating biological, psychological and social aspects of
dementia. This model is also consistent with the course of dementia not being set. Any changes caused by dementia are dependent upon an individual’s history up to that point. This sort of model encourages the focus of dementia treatment and care to be shifted away from neuropathology and on to more individual needs.
References


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CLINICAL DOSSIER
Summary of Clinical Experience

Adult Mental Health Placement
Supervisor: Onno de Boer
Location: Balham and Tooting CMHT, Springfield University Hospital, Tooting, London
Dates: From 11th October 2000 to 23rd March 2001

Clinical Experience
Clients seen were males and females (age range 19-47 years) from a variety of cultural backgrounds. Presenting problems included: panic attacks, depression, agoraphobia, health anxiety, memory difficulties following cerebral abscess, suicidal ideation, psychosis and relationship difficulties.

Assessments used included: BAI-II, BDI-II, WAIS-III, WMS-III, NART, Millon Index of Personality Styles.

Additional experience included being a member of a reflecting team in a family therapy clinic on a weekly basis.

People with Learning Disabilities Placement
Supervisor: Dr Jane Edmonds
Location: Eastbourne and County Healthcare NHS Trust CLDT, Hailsham, East Sussex
Dates: From 4th April 2001 to 21st September 2001

Clinical Experience
Clients seen were males and females (age range 19-68 years) from a White British background with different degrees of learning disability. Presenting problems included: Tourette’s syndrome, anxiety, autism, challenging behaviour, PTSD, dementia and low mood.

Assessments used included: Life Experiences Checklist, WAIS-III, Adaptive Behavioural Assessment System, HONOS-LD, Motivation Assessment Scale, BAI, Ravens Standard Matrices, Severe Impairment Battery, Dementia Rating Scale, Understanding Ambiguity, Family Relations Test and Children’s Impact of Events Scale.
Additional experience included co-facilitating a group for men with Down's syndrome focusing on consciousness raising and identity issues.

**Child and Young People Placement**

Supervisors: Ruth Armstrong and Dr Kirsty Grieve  
Location: Child and Adolescent Psychology Service, Sutton Hospital, Sutton, London  
Dates: From 10th October 2001 to 22nd March 2002

**Clinical Experience**

Clients seen were males and females (age range 2-15 years) from a predominantly White British background. Presenting problems included: anxiety, PTSD, encopresis, sleeping difficulties, behavioural difficulties, family relationship difficulties and low mood.

Assessments used included: WISC-III, Children's Memory Test, Connor's assessments, Kinetic family drawing, Draw-a-Person, Family Relations Test, Culture-Free Self-esteem Inventory, All About Me, Perceptions of Diabetes Questionnaire, WORD, WAND, TEACH, Children's Impact of Events Scale, State-trait Anxiety Inventory for Children, Strengths and Difficulties Questionnaire.

**Older People Placement**

Supervisor: Clare Crellin  
Location: Linwood CMHC, Haywards Heath, West Sussex  
Dates: From 3rd April 2002 to 20th September 2002

**Clinical Experience**

Clients seen were males and females (age range 66-88 years) from a predominantly White British background. Presenting problems included: low mood, panic attacks, health anxiety, general anxiety, psychological dependency on medication and dementia.

Assessments used included: BDI-II, BAI, BHS, HADS, MCMI-II, Trail Making Test, MEAMS, RBMT and WAIS-III.

**Mental Health in Learning Disabilities Specialist Placement**

Supervisor: Dr Hedy Ditchfield  
Location: Lambeth CLDT, Brixton, London  
Dates: From 16th October 2002 to 28th March 2003
Clinical Experience
Clients seen were males and females (age range 17-45 years) from a range of cultural backgrounds. Presenting problems included: different degrees of learning disability, challenging behaviour, autism, fire setting, autism, Sotos syndrome, psychosis, sex offending and anxiety.

Assessments used included: Victim Empathy Scale, Sex Offenders Self Appraisal Scale, Sex Offence Information Questionnaire-revised, SVR-20, QACSO (sex offender attitude questionnaire), WAIS-III, Fire Assessment Scale, Mini PAS-ADD, Hayling and Brixton tests and BDI.

This placement involved work in both a CLDT and a specialist in-patient unit for people with a learning disability and mental health problems.

Neuropsychology Specialist Placement
Supervisors: Dr Heather Liddiard and Lisa Jones-Woodard
Location: Community Neuropsychology Service, Broad Green Centre, Croydon, London
Dates: From 9th April 2003 to 26th September 2003

Clinical Experience
Clients seen were males and females (age range 25-65 years) from a predominantly White British background. Presenting problems included: cognitive difficulties following stroke, seizure, removal of brain tumour, carbon monoxide poisoning, cardiac surgery, head injury and Multiple Sclerosis; and cognitive difficulties of unknown aetiology.

Assessments used included: WAIS-III, WMS-III, WTAR, Rey figure, HADS, Trail Making Tests, verbal fluency (FAS, animals), Graded Naming Test, WCST, Behavioural Inattention Test, Hayling and Brixton Tests, Behavioural Assessment of Dysexecutive Syndrome, Ravens Advances Progressive Matrices, Doors and People Test and AMIPB

This placement involved work in both a unidisciplinary community neuropsychology service and a multidisciplinary community neurorehabilitation team.
Adult Mental Health Case Report Summary

Assessment and Intervention for a 34-year-old Woman Presenting With Depression Who Has Been Unable to Resolve a Number of Losses

Completed in Year 1
Reason for Referral

Ms Smith was a 34-year-old woman referred to the Community Mental Health Team by her GP. She had requested counselling for feelings of low mood dating back to early 1998, when she experienced an unexpected and traumatic separation from her partner of 8 years. She had also lost her home and been made redundant since this time. Ms Smith reported that she could not function properly and her life was “up in the air”. She avoided going out and could not control her emotions, having incidents of anger and weeping. She wanted to regain control over these strong emotions and start “moving on” with her life.

Initial Formulation

Ms Smith’s difficulties were initially formulated using a task-based model of grief. This model proposes that certain “tasks of mourning” need to be completed for the individual to return to a state of equilibrium following a loss. Thus, the individual needs to be actively involved in the resolution process. The model describes four tasks of grief:

1) Accepting the reality of the loss.
2) Working through the pain of grief.
3) Adjusting to an environment in which the lost person is missing.
4) Emotionally relocating the lost person and moving on with life.

An individual can become stuck in any of these tasks, which do not occur in any set order. Ms Smith’s difficulties appeared consistent with someone who had not adjusted to life following her losses (task 3) and continued to be preoccupied and emotionally attached to her “lost” partner (task 4).

Reformulation

Initial therapy sessions used this grief formulation. However, Ms Smith’s situation then changed. Her partner suddenly and unexpectedly telephoned her and asked if she would re-start their relationship. Despite the hurt he had caused, Ms Smith found this a difficult decision because she had still had some strong feelings for him. However, she decided that getting back together with him would not be helpful for her as she would never be able to trust him again. She was encouraged to write a symbolic letter to him as part of a “goodbye ritual”.

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Following this event, Ms Smith thought her therapy needs had changed. She did not want to focus on her loss and instead wanted to concentrate only on her current problems, which she considered to be her depressive symptoms. Her difficulties were therefore reformulated using a cognitive-behavioural model (figure 1). Intervention strategies derived from this reformulation included activity scheduling, identifying negative automatic thoughts (NATs) and challenging NATs.

**Outcome**

Throughout the therapeutic process Ms Smith subjectively rated her mood on a ten-point scale (where ten indicated being very depressed and zero not depressed at all). Ms Smith’s ratings indicated her depressed mood reduced during the therapeutic process. In later sessions, she also reported lower levels of emotion associated with her negative automatic thoughts. These subjective reports of improvement in mood were also supported by reports from her family and the therapist’s opinion of her mood during therapy sessions.

Ms Smith reported a reduction in other depressive symptoms. Her appetite and sleep had improved and she engaged in more activities and found more of them pleasurable. She spent less time weeping and had started to make plans for the future (e.g. looking for a job or college course). Overall, she felt she was more in control of her life.

**Prognosis**

Ms Smith still had a number of challenges to face. She had not found a job, remained socially isolated and was very sensitive to her family’s reaction to her progress. There were also still times when she felt unable to control her emotions. Increased difficulties in any of these areas could have led to another critical incident. However, Ms Smith was in an improved position should such an incident occur. She was much more prepared to ask for help from mental health services, fear of which had left her isolated for over two years on this occasion. Further, she had been able to use therapy to start grief work and learn skills relevant to CBT (e.g. identifying and challenging NATs). Therefore, if she did experience another episode of depression, its duration and impact upon her functioning should be much reduced.
Figure 1 – A cognitive behavioural formulation of Ms Smith’s difficulties
People with Learning Disabilities Case Report Summary

Assessment and Intervention for a 23-year-old Man with a Mild Learning Disability Presenting with Post-Traumatic Stress Disorder

Completed in Year 1
**Reason for Referral**

Mr Brown was a 23-year-old man with a mild learning disability. He was referred to the community learning disability service by his social worker. The referral requested counselling for Mr Brown's fear of travelling, which had developed after he was involved in a road-traffic accident in August 2000. During a telephone conversation that followed the referral, it was also disclosed that Mr Brown frequently became distressed about the accident whilst at the day-centre.

**Initial Formulation**

From the information gathered during the assessment Mr Brown’s symptoms were thought to be consistent with Chronic Post-Traumatic Stress Disorder, as described in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition. A cognitive model of PTSD was used to formulate Mr Brown’s difficulties (see figure 1).

**Pre-trauma Factors and Trauma Characteristics:** Mr Brown's protected environment may have led him to believe that he could not cope. This negative belief could also have been reinforced by the cognitive and functional difficulties he experienced as a man with a learning disability. Mr Brown’s history of anxiety also suggested that he found the world a dangerous place.

**The Trauma Memory and Appraisals:** Many details about how Mr Brown's accident occurred were not known. As a man with a learning disability, he also experienced problems with his memory on a daily basis. It would therefore have been very difficult for him to place the trauma in an organised autobiographical context, even after the accident.

**Maintaining Factors:** Mr Brown avoided reminders of the accident (e.g. motorway travel), tried not to think or talk about it and engaged in safety behaviours during car journeys (e.g. looking around for danger). When he did try to talk about the accident, people attempted to stop him or distract him. These behaviours prevented him from challenging any of his negative appraisals (e.g. overgeneralization of threat, belief he could not cope) or organising the trauma memory.
Prior experiences - protected environment
Prior beliefs - "I cannot cope"; "the world is very dangerous".
Prior coping strategies - avoidance and reassurance seeking.
Characteristics of trauma - sudden, unpredictable, uncontrollable.

Cognitive processing during trauma
Data processing due to low intellectual ability and unpredictability of accident.
Processing difficult due to cognitive ability to manage new information.

Nature of Trauma Memory
Poorly incorporated into autobiographical memory.
Re-experienced mainly as sensory impressions.
Re-experienced as if recurring.
Prone to unintentional recall.

Negative appraisal of trauma and its sequelae
Confirmed belief that world is dangerous, leading to overgeneralization of threat.
Reinforced belief that he could not cope.
Discrepancy between emotional distress and self-image.

Matching triggers

Current Threat
Frequent emotional distress, increased anxiety and arousal, intrusive recollections.

Strategies intended to control threat/symptoms
Avoided reminders of the accident (e.g. travelling in cars)
Avoid talking about the accident
Safety behaviours whilst travelling

Arrows indicate the following relationships:

--- influences

--- leads to

--- prevents change in

Figure 1: Cognitive model applied to Mr Brown's difficulties
Intervention

Intervention aimed to alter the factors that were thought to be maintaining Mr Brown's difficulties. This primarily involved imaginai exposure (i.e. restructuring the trauma memory by detailed visualization and verbalization of the traumatic incident) and graded exposure to feared situations.

Outcome

Mr Brown, his keyworker and the trainee clinical psychologist all thought that Mr Brown’s distress had reduced as therapy progressed. For example, prior to intervention he was unable to give an account of his accident, becoming tearful and distressed when he tried to talk about it. By the time of the last session, Mr Brown was able to talk freely about the accident without any additional emotional distress or anxiety. A brief questionnaire, designed by the trainee clinical psychologist, was also completed by Mr Brown's keyworker. On the baseline administration the keyworker indicated that the accident sometimes/often caused difficulties for Mr Brown. On outcome, he indicated that the accident rarely/never had an impact on Mr Brown’s functioning.

There are no specific PTSD measures designed for use by people with learning disabilities. The Children’s Impact of Events Scale (CIES) was therefore used as a standardised outcome measure. Although Mr Brown’s total CIES score decreased by 15 points during the course of therapy, his total outcome score was still above the level considered to indicate the presence of PTSD. This appeared puzzling, given the good outcome reports from both Mr Brown and those around him. However, on closer inspection, it was seen that the majority of Mr Brown’s total outcome CIES score was on an “avoidance” scale. This probably reflected his pre-trauma anxiety level and coping style, rather than PTSD.

Mr Brown had a high level of anxiety prior to the traumatic incident. After therapy, he also reported that he remained scared of motorway journeys. However, he was hopeful this could change. He agreed a referral for further work on his general anxiety might be useful. It was envisaged that this would incorporate exposing Mr Brown to anxiety provoking situations and allowing him to try to cope with these unsupported. He could therefore develop alternative coping strategies and start to challenge his negative beliefs.
Child and Young People Case Report Summary

Assessment and Behavioural Intervention for a 9 Year-old Girl Who is Afraid of Sleeping Away From Her Parents

Completed in Year 2
Reason for Referral

Jane was a nine-year-old girl who was referred to the child psychology service by her GP. It was reported that Jane became terrified at night and therefore still slept with her parents.

Background Information

Mr and Mrs Green reported that when Jane was an infant she slept in a cot in their bedroom with no difficulty. When she was about 18 months old they bought her a bed and tried to put her to sleep in her own room. Mrs Green would wait with Jane until she fell asleep. During the night, Jane would wake up and go to her parents’ bedroom. If they returned her to her own bed she started crying. Mr and Mrs Green reported that they found it distressing when Jane cried. They therefore comforted her and allowed her to sleep with them.

Jane’s parents had asked their health visitor for help with Jane’s night waking. They were advised that at bedtime they should either gradually sit further away from Jane or leave Jane alone for increasingly long periods of time. Both these techniques were unsuccessful. The health visitor next suggested locking Jane in her room and leaving her to “cry herself to sleep”. Mr and Mrs Green tried this strategy. However, Jane was still crying two hours after they put her in her room so they decided to go and comfort her. When they unlocked the door, they found that at some point Jane had vomited. They found this very distressing and decided not to go back to the health visitor for more advice. Instead, they let Jane sleep in their bed and hoped she would “grow out of” her sleeping difficulties. As Jane got older, her parents remained cautious about encouraging her to sleep in her own room. They reported being worried that she would become extremely distressed again and then be too tired for school.

Initial Formulation

Jane’s problems were formulated in the context of the developmentally appropriate sleeping difficulties she experienced when she was about 18 months old (see figure 1). It was hypothesised that through classical conditioning she had learned to associate anxiety, distress and vomiting with sleeping away from her parents. She therefore feared these reactions/events happening again and avoided sleeping away from her parents. Sleeping with her parents meant that extinction of this learned association did not occur and Jane had no opportunity to develop and use self-soothing skills to help her sleep.
Predisposing Factors
Jane may have had difficulty regulating her arousal levels, leading her to seek comfort from her parents.

Jane's parents found it difficult to let her cry, which limited her opportunities to develop self-soothing skills.

Maintaining Factors
Jane did not sleep away from her parents. She therefore had no opportunity to develop her self-soothing skills and her learned association was not extinguished.

Jane's conditioned response was reinforced by her failed attempts to sleep at friends' houses.

For Mr and Mrs Green, sleeping with Jane was negatively reinforced.

Mr and Mrs Green believed Jane would "grow out of" her difficulties.

Precipitating Factors
Jane learned to associate sleeping away from her parents with anxiety and distress. She therefore feared this event and avoided it.

CURRENT SLEEP PROBLEM
Jane was afraid to sleep away from her parents.

Protective Factors
The family had come to a point where they accepted there was a problem.

There was good support amongst family members.

Jane was motivated to change – she wanted to go on a Brownie camp, school trips and stay over at friends' houses.

Figure 1: Formulation of Jane's difficulties
Mr and Mrs Green reported finding it distressing when Jane cried. There had also been a number of occasions when Mr and Mrs Green let Jane sleep with them and she stopped crying. It was therefore hypothesised that letting Jane sleep with them had been negatively reinforced through operant conditioning – it was made more likely to occur because it resulted in the removal of an aversive stimulus (Jane crying).

**Intervention**

A graded exposure hierarchy was constructed with Jane, in which she was gradually and repeatedly exposed to her feared situation (sleeping away from her parents) with anxiety-management strategies in place. This allowed Jane to develop her self-soothing skills and extinguish her learned association. It also reinforced alternative behaviours for Mr and Mrs Green (other than sleeping with Jane). Jane had made a written contract for both herself and her mother to provide additional motivation for the family to continue with the graded exposure program.

**Outcome**

Jane achieved her initial goal, which was to go on a weekend Brownie camp that involved sleeping away from her parents. Mrs Green’s goal was for Jane to be able to fall and stay sleep in her own bed without support. Although Jane had progressed through most stages of her graded-exposure program, she still needed support whilst she was falling asleep. Nevertheless, both Jane and her mother were more confident that they had the skills to continue to work on this aspect of Jane’s sleeping behaviour. In the final session the family reported other positive outcomes of the intervention. Mr and Mrs Green were having better quality sleep and no longer had to sleep apart. Jane reported that she felt more like a “normal” girl.

**Prognosis**

The trainee thought the changes produced by the intervention were likely to be maintained. Jane’s sleeping behaviour suggested she was developing her self-soothing skills and her learned association was being extinguished. Also, Mr and Mrs Green no longer invited Jane to their bed when she could not sleep and instead looked for ways to help her sleep in her own bed.
Older People Case Report Summary

Assessment of an 84 Year-old Man
Referred for Treatment of Depression

Completed in Year 2
Reason for Referral

Mr Jones was an 84-year-old man who was referred to the Older Adult Clinical Psychology Service by an older adult day hospital. They requested that a psychologist assess Mr Jones with a view to suggesting a therapeutic approach to treating his depression.

Background Information

Mr Jones first presented to mental health services in 1997. He had been feeling tired and physically unwell for the previous two years. He had no interest in going out, no energy, poor appetite and no motivation. He was prescribed an anti-depressant and his situation slowly improved over the course of about 18 months. In April 1999 Mr Jones said that he felt back to his normal self. He was therefore discharged, but continued to attend the day hospital for two days each week.

In October 2001 the Day Hospital was temporarily closed so that urgent repair work could be completed. During this period, Mr Jones was visited at home by an Occupational Therapist. She found that he spent most of his time in bed and initiated very few activities. His wife was becoming increasingly tired and stressed through having to do everything for him. He was prescribed various antidepressant medications, but they had had only limited benefit. Mr Jones’ situation was monitored when the day hospital re-opened. When no improvement was noted the present referral to the Older Adult Clinical Psychology Service was made.

At assessment Mr Jones reported his main difficulty to be that he always felt tired, despite sleeping well during the night. He had no motivation to do anything and would often go back to bed after breakfast. Mr Jones reported that he used to enjoy a number of activities, including watching a good film, going to the theatre and reading. However, since he had been feeling “depressed” he had no urge to do these things. He did not go out alone and had stopped driving, as “I think it’s very unwise to get into a car when I’m not feeling 100%”. He felt unsatisfied with his current level of activities. He had previously had a very successful career as an electrical engineer before retiring at the age of 63.

It was observed that Mr Jones had a number of word-finding difficulties during the assessment. Most noticeably, he could not remember the name of one of his granddaughters and had to check it on her graduation photograph. Considerable circumlocution (i.e. the use
of many words to communicate a point when more concise sentences are possible) was also evident.

Initial Assessment

The Middlesex Elderly Assessment of Mental State (MEAMS) was administered as a brief cognitive screen. Mr Jones failed three sub-tests, which gave him an overall MEAMS screening score of nine, which is in the "borderline" range. Mr Jones also completed two mood questionnaires, the Beck Depression Inventory-II (BDI-II) and the Hospital Anxiety and Depression Scale (HADS). His BDI-II indicated he had symptoms consistent with mild depression. His HADS indicated that he had no clinically significant symptoms of anxiety, but some symptoms of depression.

Initial Hypotheses

Two initial hypotheses were considered:

1) Mr Jones' current difficulties are the result of depression.

2) Mr Jones' current difficulties are predominately the result of an organic brain disorder.

The trainee and supervisor agreed there was enough evidence suggesting Mr Jones might have an organic brain disorder to warrant further psychometric testing. This would aim to answer the question, "Are Mr Jones' difficulties the result of an organic brain disorder or depression?" and hence provide evidence for or against the above hypotheses. The Wechsler Adult Intelligence Scale, Third Edition (WAIS-III) was therefore administered. This test assesses the major dimensions of general intelligence.

Results

Mr Jones was fully cooperative and appeared motivated throughout the assessment. However, he was extremely slow on some sub-tests, particularly those that required him to give some sort of verbal description in his response. He was also noticeably frustrated with his performance and thought he should be doing much better.
Mr Jones' overall WAIS-III performance was considerably below expectations based upon his educational and occupational history. He demonstrated a particular weakness on sub-tests assessing non-verbal and spatial skills, which would appear to be relevant to the work of an electrical engineer. In contrast, his performance on many sub-tests thought to be more resistant to brain injury was consistent with expectations. The size of variation between many of his IQ and Index scores was also statistically significant and rare in the general population. This suggested these differences were the result of an acquired deficit and were not a natural occurrence.

Formulation

Mr Jones' pattern of results was considered to be more typical of organic changes than depression. On this basis, he was referred for a CT head scan. The scan results, when combined with the deficits highlighted in the psychometric assessment, suggested Mr Jones had an organic impairment of vascular origin.

Outcome

After receiving the results, the day hospital began investigating possibilities for extending Mr Jones' structured daytime activities. The trainee clinical psychologist also reported the assessment findings to Mr and Mrs Jones. Both reported a degree of relief that they had some idea about the cause of Mr Jones' difficulties. They were offered further sessions to discuss their thoughts and feelings about the situation. However, they declined because they felt they were able to cope and begin future care planning without additional specialist psychological support.
Mental Health in Learning Disabilities
Case Report Summary

Risk Assessment of a Sex Offender with a Significant Learning Disability

Completed in Year 3
Reason for Referral

Mr Heath was a 45 year-old man with a significant learning disability. He was also a Schedule One sex offender. In 2002 he moved from a probation service hostel to a flat in a neighbouring borough. The learning disability care management team of that area referred Mr Heath to a forensic psychiatrist for an opinion on his current risk of re-offending. The psychiatrist felt unable to identify an overall level of risk. However, he did recommend that Mr Heath should move again, as his flat was situated opposite a primary school. No other appropriate accommodation could be found in that area. Therefore, after eight months away, Mr Heath had to return to his home borough where a flat could be found.

Following Mr Heath’s return, the Psychology service of the local Community Learning Disability Team (CLDT) decided that a comprehensive assessment of his current risk was needed. Input from the Trainee Clinical Psychologist was requested in order to help with this assessment.

Risk Assessment of Learning Disabled Sex Offenders

Risk assessment has been described as the process of collecting, recording and interpreting data in order to communicate and implement a risk management plan. It is therefore aimed at preventing further offences. However, there is very little literature about risk assessment with people who have a learning disability. It has been suggested that the sex offender should be the focus of any assessment, in that the information derived should be used to inform a psychological formulation of their sex offending behaviour. This formulation would then provide the rationale for any interventions and any conclusions about current risk. Assessment should also establish a baseline against which changes, including changes in risk factors, can be systematically evaluated.

The use of a formal structure to guide clinical judgement was considered to be the best currently available method for assessing Mr Heath’s level of risk. This assessment would be used to inform a psychological formulation of Mr Heath’s sex offending behaviour.

The Sexual Violence Risk-20 (SVR-20) was chosen as the framework for Mr Heath’s assessment. However, the presence of risk factors was evaluated in the light of Mr Heath’s learning disability, as well as through the SVR-20 guidelines.
A number of measures of cognitive distortions were also administered. These were designed by a specialist forensic in-patient service for use with people with learning disabilities. However, there was no research literature on these measures. They were therefore interpreted qualitatively with the aim of eliciting useful information about Mr Heath’s thoughts and beliefs about his sexual offending. The Beck Depression Inventory (BDI) was administered as a measure of current mood.

Results

Formulation

A primary aim of this assessment was to inform a formulation about Mr Heath’s sex offending behaviour. A cognitive behavioural model was used (see figure 1).

<table>
<thead>
<tr>
<th>Historic Variables</th>
<th>Mediating Variables</th>
<th>Dependent Variables</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intellectual deficits</td>
<td>Social problem solving</td>
<td>Sex Offending Behaviour</td>
</tr>
<tr>
<td>Significant LD</td>
<td>Poor understanding of poor understanding of Poor understanding of poor understanding of poor understanding of poor understanding of other’s behaviour - (e.g. other’s behaviour - (e.g. other’s behaviour - (e.g. other’s behaviour - (e.g. on public transport, in on public transport, in on public transport, in on public transport, in on public transport, in relationships). relationships). relationships). relationships).</td>
<td>Stress</td>
</tr>
</tbody>
</table>

Figure 1: A Formulation of Mr Heath’s sex offending behaviour (from Nezu, Nezu & Dudek, 1998).

Current Risk

From the data collected, Mr Heath appeared to be best understood in terms of the SVR-20’s “moderate risk” category. The reason that Mr Heath’s risk was moderate and not high was probably because of his engagement with services. If this support changed, the risk of him...
offending was likely to increase. Regular re-evaluation was therefore important and this was highlighted in the risk assessment report. The structure of this report also provided a systematic method for monitoring the impact that any change in Mr Heath’s circumstances would have on his level of risk.

Possible Future Interventions

From the formulation, two areas of intervention were identified. Firstly, further analysis of the measures used to investigate Mr Heath’s thoughts and beliefs about his sexual offending might provide the basis for cognitive work. However, there is limited research on the use of cognitive approaches with this population. Secondly, Mr Heath’s support staff could be taught to monitor the “stresses” identified in the formulation for any change. This could also help them target their support time to helping Mr Heath in these areas (e.g. building appropriate friendships to reduce the risk of social isolation).
RESEARCH DOSSIER
# LOG OF RESEARCH EXPERIENCE

<table>
<thead>
<tr>
<th>Research Skill/Experience</th>
<th>Description of how research skill/experience acquired</th>
<th>Date research skill/experience acquired</th>
</tr>
</thead>
</table>
| Conduct a literature search | Literature search on grief models and grief work for use in client work and case report (PsychINFO).  
Literature search on CBT and IPT for depression for use in client work and essay (PsychINFO).  
Literature search on perceptions of/attitudes towards systemic family therapy for Service Related Research Project (PsychINFO; MEDLINE).  
Literature search on: psychological approaches to PTSD; PTSD and people with learning disabilities; CBT with people with learning disabilities. For use in client work and case report (PsychINFO).  
Literature search on: functional analysis of challenging behaviour; communication hypothesis and challenging behaviour; challenging behaviour and people with learning disabilities. For use in essay (PsychINFO).  
Literature search on: sleeping difficulties/problems in children; behavioural work with children and families. For use in client work and case report (PsychINFO).  
Literature search on OCD in children; panic disorder in children; CBT with children; therapy with children. For use in client work, case report and for presentation to members of child psychology service (PsychINFO).  
Literature search on differential diagnosis of dementia; cognitive assessment of dementia; cognitive assessment with older people. For use in client work and case report (PsychINFO; MEDLINE).  
Literature search on outcome of dementia; course of dementia; psychological interventions for dementia; use of drugs to treat dementia. For use in client work and essay (PsychINFO; MEDLINE). | Sept 2000-March 2001  
April 2001-September 2001  
October 2001-March 2002  
April 2002-September 2002 |
<p>| Conduct a literature search (continued) | Literature search on: Downs syndrome and executive functioning; Downs syndrome and neuropsychology; Downs syndrome and memory; Downs syndrome and long-term memory for Major Research Project; memory systems; memory assessment and people with learning disabilities; dementia and Downs syndrome; executive functioning; modularity of brain functioning. For Major Research Project (PsychINFO; MEDLINE). Literature search on fire setting and people with a learning disability for clinical work (PsychINFO). Literature search on: sex offender assessment; sex offenders with a learning disability; risk assessment. For use in client work and case report (PsychINFO). Literature search on Multiple Sclerosis for clinical work and presentation in supervision (PsychINFO). Literature search on cognitive impairment following cardiac surgery for clinical work (PsychINFO). | January 2002-July 2002 | October 2003-March 2003 | April 2003-July 2003 |
| Formulate a specific research question | Specific research question generated for Service Related Research Project (Do training/understanding and perceptions of systemic family therapy, professional and/or family background influence whether mental health professionals refer to a family therapy service?) | March 2001 |</p>
<table>
<thead>
<tr>
<th>Task</th>
<th>Description</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Formulate a specific research question (cont.)</td>
<td>Specific research question generated for Major Research Project (Are there differences between the long-term memory and/or executive functioning of adults with Downs syndrome and adults with a learning disability of non-specific aetiology?)</td>
<td>June 2002</td>
</tr>
<tr>
<td>Write a brief research proposal</td>
<td>Brief research proposal submitted for Service Related Research Project submitted to university and field supervisors. Brief research proposal submitted for Major Research Project submitted to university supervisor.</td>
<td>February 2001</td>
</tr>
<tr>
<td></td>
<td></td>
<td>January 2002</td>
</tr>
<tr>
<td>Write a detailed proposal/protocol</td>
<td>Detailed research proposal for Major Research Project submitted to university supervisor, field supervisor, relevant ethics committees and NHS Trust Research and Development Steering Group.</td>
<td>July-December 2002</td>
</tr>
<tr>
<td>Obtain appropriate supervision/collaboration for research</td>
<td>University and field supervision arranged for Service Related Research Project. Group supervision arranged for Qualitative Research Project. University, field and statistics supervision arranged for Major Research Project.</td>
<td>January 2001</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Jan 2002-July 2003</td>
</tr>
<tr>
<td>Write a participant information sheet and consent form</td>
<td>Information sheet and consent form designed for use with people with learning disabilities</td>
<td>July 2002</td>
</tr>
<tr>
<td>Judge ethical issues in research and amend plans accordingly</td>
<td>Devised clear recruitment and consent procedures and adapted information sheets and consent forms for learning disabled population when designing Major Research Project.</td>
<td>July 2003</td>
</tr>
<tr>
<td>Obtain approval from a research ethics committee</td>
<td>Approval from two Local Research Ethics Committees and university ethics committee obtained for Major Research Project.</td>
<td>July-December 2002</td>
</tr>
<tr>
<td>Collect data from research participants</td>
<td>Data collected via individually completed questionnaires constructed by the Trainee for Service Related Research Project. Data collected from focus group for Qualitative Research Project. Data collected through psychometric testing for Major Research Project</td>
<td>April-May 2001</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Jan 2003-June 2003</td>
</tr>
<tr>
<td>Set up a data file</td>
<td>Data file for Service Related Research Project set up using SPSS Data files for Major Research Project set up using SPSS.</td>
<td>May 2001</td>
</tr>
<tr>
<td></td>
<td></td>
<td>January 2003</td>
</tr>
<tr>
<td>Activity</td>
<td>Description</td>
<td>Date</td>
</tr>
<tr>
<td>----------------------------------------------</td>
<td>-----------------------------------------------------------------------------</td>
<td>------------</td>
</tr>
<tr>
<td>Analyse qualitative data</td>
<td>Focus group transcript analysed using Interpretative Phenomenological Analysis for Qualitative Research Project.</td>
<td>June 2003</td>
</tr>
<tr>
<td>Interpret results from data analysis</td>
<td>Results interpreted and discussed for Service Related Research Project. Results interpreted and discussed for Qualitative Research Project. Results interpreted and discussed for Major Research Project.</td>
<td>May 2002</td>
</tr>
<tr>
<td>Defend research project at an oral examination</td>
<td>Viva for Major Research Project.</td>
<td>September 2003</td>
</tr>
</tbody>
</table>
Service Related Research Project

Why Do Some Health Professionals Not Refer to Systemic Family Therapy Services? An Initial Study

Completed in Year 1
Why Do Some Health Professionals Not Refer to Systemic Family Therapy Services?
An Initial Study

Abstract

Since their development in the 1950s, systemic interventions have become an established part of NHS mental health services (Dallos & Draper, 2000). However, members of a family therapy team thought that many mental health professionals still did not consider systemic family therapy services when planning interventions. When consulted further, the therapists suggested a number of possible influences on referral behaviour. These included amount of training in and understanding of systemic family therapy, perceptions of systemic family therapy, professional background and referrers' family backgrounds. To explore whether these factors did influence referrals, a questionnaire was designed and distributed to all professionals in 7 CMHTs and one ACT team. The results indicated that there was a good general knowledge both that the family therapy clinic existed and of the referral procedure. There was a significant difference between referrers and non-referrers on their ratings of understanding of systemic family therapy. However, the discussion highlighted a number of limitations of the study. It was therefore proposed that results were best used as a platform for further research within the family therapy service.

Acknowledgements

The author would like to thank the research supervisors, family therapy team and team secretaries who contributed to the completion of this study.
Introduction

The systemic approach to psychological functioning takes as its focus the systems in which people operate. This is usually applied to the context of the family. When approaching mental health problems, systemic therapists concentrate on interpersonal processes within the system (or family) rather than an individual's symptoms.

Systemic approaches developed in the 1950s (e.g. Ackerman, 1958; Bateson, Jackson, Haley & Weakland, 1956). Systemic family therapy has since expanded and is now an established part of the NHS (Dallos & Draper, 2000). Recent NHS policy (National Service Framework for Mental Health; Department of Health, 1999) stresses the importance of involving and supporting families (standard 6) and offering service users referral to specialist services (standard 2). The current NHS focus on evidence-based practice is reflected by a growing body of research supporting the use of family interventions for a range of mental health difficulties. These include depression (e.g. Leff et al., 2000), psychoses (e.g. Fadden, 1998) and anxiety disorders (e.g. Baucom, Shoham, Mueser, Daiuto & Stickle, 1998). Therefore, it seems that most mental health professionals within the NHS should consider systemic approaches when planning interventions.

Despite this research evidence, members of a family therapy team were concerned that many health professionals did not consider referring to systemic services. A brief review of the literature showed some support for this concern. There have been relatively few systemic initiatives in mental health services (Kuipers, Birchwood & McCreadie, 1992). In the field of Clinical Psychology, one survey reported that only 6% of Division of Clinical Psychology respondents claimed the systems or family approach was their main theoretical orientation (Norcross, Brust & Dryden, 1992). Fredman (2001) argued that as a profession clinical psychologists do not promote the systemic approach and Dallos and Draper (2000) reported that systemic approaches continue to be the choice of a minority of therapists.

In clinical discussions on this issue with members of the family therapy team, possible reasons why some local health professionals did not refer to the family therapy service were suggested. These included their understanding of and/or training in systemic family therapy, their perceptions of systemic family therapy and their family and professional backgrounds.
A review of the literature found support for some of these suggestions. Gilleard, Lieberman and Peeler (1992) surveyed local professionals' attitudes towards a new family therapy service for older adults after they had a continuously low referral rate. They found that although there was a positive attitude towards the idea for the service, other perceptions (e.g. understanding of the approach, reservations about older people’s ability to change) influenced referral behaviour. Other research has also investigated the perceptions referrers have of clinical psychology services (e.g. Latchford & Royle, 1998; Chadd & Svanberg, 1994) on the basis that this affects how those services are used.

With regard to professional background, it has been highlighted that clinical psychology training does not offer a strong theoretical base for trainees to develop their systemic thinking and that this influences later clinical practice (Vetere, 2001). Referral behaviour may also be influenced by the client groups a professional has worked with, through an historical association between certain client groups and family interventions. For example, much early systemic work focussed on the development of approaches to schizophrenia (e.g. Bateson, Jackson, Haley & Weakland, 1956; cited in Barker, 1986) and there continues to be much work in his area (e.g. Dixon, Adams & Lucksted, 2000). Therefore, aspects of the professional background of mental health workers (e.g. discipline, contact with certain client groups) may affect their understanding of systemic approaches and use of family therapy services.

The author found no previous research on the influence of family background on referral behaviour. However, the family therapy team speculated on a theoretical link between them. Systemic approaches consider various levels of a system and previous research has examined the influence of family background on therapist’s behaviour in the therapy system (e.g. McGoldrick, 1982). Referrers are part of the wider health system and can therefore also be considered. Carter and McGoldrick (1989) conceptualised the family as a system moving through time, continually adapting to its changing context. It was suggested that the experience of renegotiating relationships within a changing family system (e.g. birth of a sibling, onset of a new relationship) could facilitate the understanding of systemic ideas and thus influence referral behaviour.

The suggestions of the family therapy team were used to generate hypotheses about differences between referrers and non-referrers to the family therapy service. These are outlined below:
1) Referrers to family therapy services will report a greater level of training and/or understanding of systemic family therapy than non-referrers.

2) Referrers' perceptions of family therapy services will indicate a more positive image of those services than non-referrers.

3) Professional background will influence referral behaviour.

As well as these clear hypotheses, the study aimed to begin exploring any possible influence of the family background of mental health professionals on their referral behaviour.

**Method**

**Setting**

The study was based in an established family therapy clinic that is part of a Community Mental Health NHS Trust. The Trust serves a large inner city population. Referrals to the clinic come via CMHTs, GPs, consultants and social services within the Trust's area.

**Measures**

This study required that a variety of data be collected from a number of different professionals in the local area. Given the constraints of the study (particularly time and limited budget) a questionnaire was thought to be the best method of data collection. The researcher developed a questionnaire (Appendix A) that was split into 4 main parts, each one focussing on a different hypothesis. Closed questions were used to facilitate comparisons between the referrer and non-referrer groups and reduce the time needed to answer the questions. A draft version of the questionnaire was piloted on the research supervisor and members of the family therapy service, before a final version was distributed. No formal statistical analysis was used to determine the validity or reliability of the measure, but these issues were addressed during piloting.

The first section of the questionnaire looked at past referral behaviour, understanding of systemic family therapy and training in systemic family therapy. Referral behaviour was elicited by respondents circling fixed answers. Self-perceived levels of understanding and training were measured via 5-point rating scales.
The second part examined respondents’ perceptions of systemic family therapy. It was developed from discussions with clinicians in the family therapy service and constructs identified as important in the literature on GP’s perceptions of clinical psychologists (Chadd & Svanberg, 1994). These included usefulness, cost-effectiveness, evidence-base, level of training and effectiveness. The perceptions were transformed into statements about systemic family therapy in the questionnaire (e.g. “systemic family interventions are cost-effective”). Respondents rated on 5-point scales (“strongly disagree” to “strongly agree” with “neither agree nor disagree” as a mid-point) their agreement with these statements.

Respondents were also asked to rate on 5-point scales (“not at all useful” to “very useful” with “moderately useful” as a mid-point) how useful they perceived systemic interventions to be for some specific mental health problems (Anxiety Disorders, Bi-Polar Affective Disorder, Depression, Obsessive-Compulsive Disorder, Psychosis, Relationship/Family Difficulties). This list was derived from discussions with members of the family therapy service. Space was left for respondents to list other mental health problems they felt systemic interventions might be effective for.

The third section of the questionnaire looked at professional background. Respondents were asked to record their profession, current work setting and number of years of professional experience. They were also asked to select their preferred model of working, apart from medication, from a list that was derived from discussions with the field supervisor (non-directive/counselling; cognitive/behavioural; psychodynamic; family/systemic; other). The level of professional contact respondents had with some specific mental health problems (Anxiety Disorders, Bi-Polar Affective Disorder, Depression, Obsessive-Compulsive Disorder, Psychosis, Relationship/Family Difficulties) was measured via 5-point scales (“none” to “very high” with “moderate” as a mid-point). A space was left where other mental health problems commonly worked with could be listed.

The final section of the questionnaire collected information about family background. The research was interested in respondents’ experiences of renegotiating relationships within a family system. The information collected was therefore based on what is needed to complete a very simple genogram (i.e. age, gender, number of siblings, whether has a partner, number of children). Information about parents was not gathered as it was felt this might deter people from responding. The whole section was also made optional for this reason. However, its importance to the study was stressed.
Participants and Procedure

Both the researcher and field supervisor thought that ethics approval was unnecessary for this study because it was anonymous and used a sample of health professionals. However, following recent changes in the NHS (Department of Health, 2001), this would probably not be the case for any future similar studies.

This study was based in a local family therapy service and required a variety of mental health professionals. The sample was therefore taken from seven local Community Mental Health Teams (CMHTs) and one Assertive Community Treatment (ACT) team. As an example of how different professions are represented in CMHTs, one that was surveyed consisted of 4 psychiatrists (including specialist registrars and SHOs on rotation), a clinical psychologist, 3 nurses, 3 social workers, an occupational therapist and a mental health support worker. The ACT team is composed of clinical case managers, who are health professionals from a variety of backgrounds, and support workers.

These teams were contacted by telephone and the secretaries agreed to distribute questionnaires to all team members. Completed questionnaires were returned to the respective team secretaries and collected by the researcher some weeks later. An a priori power analysis indicated that for a power of 0.7 with a large effect size, 42 subjects were needed. To maximise the response rate the team secretaries agreed to keep reminding non-respondents to complete their questionnaires. A covering letter (Appendix B) was also included with the questionnaires. This informed respondents about the nature of the research, who to pass the questionnaire to and ensured confidentiality.

Results

In total 125 questionnaires were distributed. The response rate of 44 returns (35.2%) was typical for this sort of study (e.g. McNeill, 1990). The distribution of the returns amongst the different professions is outlined in table 1.
Table 1: Returned questionnaires by profession.

<table>
<thead>
<tr>
<th>Profession</th>
<th>No. of returns</th>
<th>% of total returns</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychiatrist</td>
<td>12</td>
<td>27.3%</td>
</tr>
<tr>
<td>Social Worker</td>
<td>11</td>
<td>25%</td>
</tr>
<tr>
<td>Nurse</td>
<td>10</td>
<td>22.7%</td>
</tr>
<tr>
<td>Psychologist</td>
<td>7</td>
<td>15.9%</td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td>2</td>
<td>4.5%</td>
</tr>
<tr>
<td>Support Worker</td>
<td>1</td>
<td>2.3%</td>
</tr>
<tr>
<td>Clinical Case Manager</td>
<td>1</td>
<td>2.3%</td>
</tr>
</tbody>
</table>

Statistical Analysis

The questionnaire collected ordinal and nominal data, and the sample size was small. Non-parametric statistical analyses were therefore selected. The Mann-Whitney test was used to examine differences between the referrer and non-referrer groups on ordinal data. For nominal data, Fisher’s exact test was used. This examines the significance of the variation between observed and expected frequencies.

When testing some of the hypotheses, multiple statistical analyses were carried out on the same data. In these cases, a family-wise Bonferonni correction (Everitt & Wykes, 1999) was used. This is a conservative correction, but it maintains statistical integrity when multiple statistical tests are employed. Corrected significance levels are indicated with the relevant statistics.

Past Referral Behaviour

Of the total respondents, 40 (90.9%) were aware that the family therapy service existed and 33 (75%) knew how to refer to the service. Eighteen (40.9%) had referred to the service in the past and 26 (59.1%) had not. Of the group who had not referred to the service before, 21 (80.8%) reported they would consider doing so. The remaining 5 (19.2%) respondents who had not referred did not answer the question. Therefore, nobody who returned a questionnaire stated they would not consider referring to the family therapy service.
Hypothesis 1 - Training in and Understanding of Systemic Family Therapy

The respondents' ratings of their level of understanding and training in systemic family therapy are summarised in table 2. The mean understanding scores of both the referrer (3.56) and non-referrer (3.04) groups were equivalent to a point on the response scale between "moderate" and "quite good". The difference between referrers' and non-referrers' understanding scores was significant. The mean training scores of both the referrer (2.5) and non-referrer (2.19) groups were equivalent to a point on the response scale between "low" and "moderate". The difference between referrers' and non-referrers' training scores was not significant.

<table>
<thead>
<tr>
<th></th>
<th>Referrers</th>
<th>Non-referrers</th>
<th>Overall</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Understanding</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>3.56</td>
<td>3.04</td>
<td>3.25</td>
<td>z (18, 26) = -2.32, p=0.02</td>
</tr>
<tr>
<td>Standard Deviation</td>
<td>0.62</td>
<td>0.77</td>
<td>0.75</td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>3 - 5</td>
<td>2 - 5</td>
<td>2 - 5</td>
<td></td>
</tr>
<tr>
<td><strong>Training</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>2.5</td>
<td>2.19</td>
<td>2.32</td>
<td>z (18, 26) = -0.886, p=0.375</td>
</tr>
<tr>
<td>Standard Deviation</td>
<td>1.1</td>
<td>0.98</td>
<td>1.03</td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>1 - 5</td>
<td>1 - 4</td>
<td>1 - 5</td>
<td></td>
</tr>
</tbody>
</table>

Table 2: Training and understanding scores of referrers and non-referrers.

Hypothesis (1) was therefore supported.

Hypothesis 2 - Perceptions of Systemic Family Therapy

The different perceptions of systemic family therapy outlined in the method were measured on 5-point rating scales. It was possible to combine the various perception ratings into a single construct of perceptions of systemic family therapy because Cronbach's alpha demonstrated such a scale had internal consistency (alpha=0.64). The range of this scale was 0 – 25, with a high score indicating a respondent strongly agreed with statements about
systemic family therapy (e.g. "The use of systemic family interventions has a good evidence base"). These perception construct scores are summarised in table 3. The difference between the perception scores of referrers and non-referrers was not significant.

Respondents were also asked to rate on 5-point scales how useful they thought systemic family therapy was for some specific mental health problems (Anxiety Disorders, Bi-Polar Affective Disorder, Depression, Obsessive-Compulsive Disorder, Psychosis, Relationship/Family Difficulties). It was possible to take these ratings as a single scale of usefulness of systemic family therapy because Cronbach’s alpha demonstrated the scale had internal consistency (alpha=0.81). The range of this scale was 0 – 25, with a high score indicating a perception that systemic family therapy is very useful for a range of mental health difficulties. These usefulness constructs are summarised in table 3. There was no significant difference between the referrer and non-referrer groups.

<table>
<thead>
<tr>
<th></th>
<th>Referrer</th>
<th>Non-referrer</th>
<th>Overall</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Perceptions</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>19.12</td>
<td>18.72</td>
<td>18.84</td>
<td></td>
</tr>
<tr>
<td>Standard Deviation</td>
<td>2.34</td>
<td>1.67</td>
<td>1.95</td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>16 – 24</td>
<td>15 – 22</td>
<td>15 – 24</td>
<td></td>
</tr>
<tr>
<td><strong>Usefulness</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>20.87</td>
<td>21.45</td>
<td>21.24</td>
<td></td>
</tr>
<tr>
<td>Standard Deviation</td>
<td>5.05</td>
<td>4.26</td>
<td>4.48</td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>10 – 29</td>
<td>14 – 30</td>
<td>10 – 30</td>
<td></td>
</tr>
</tbody>
</table>

Table 3: Summary of perception and usefulness constructs.

Hypothesis (2) was therefore not supported.

Some respondents thought systemic family therapy could be useful in others areas. Areas suggested were personality disorders, eating disorders, anger, drug and alcohol addiction, sexual difficulties, marital problems, child behavioural problems and refugees. Some thought that systemic interventions could be useful for any problems, regardless of diagnosis.
Hypothesis 3 - Professional Background

The different referral rates of each profession are summarised in table 4. Psychologists had the highest referral rate (57.1%), followed by psychiatrists (50%) and nurses (40%). Of the referrers, the largest professional group was psychiatrists (33.3%) followed by nurses (22.2%). The low response rate of the study meant it was not possible to compare the frequency of referrers and non-referrers by professional group.

<table>
<thead>
<tr>
<th>Profession</th>
<th>No. of profession who had referred</th>
<th>% of profession who had referred</th>
<th>% of total referrer group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychiatrist</td>
<td>6</td>
<td>50%</td>
<td>33.3%</td>
</tr>
<tr>
<td>Social Worker</td>
<td>4</td>
<td>18.2%</td>
<td>11.1%</td>
</tr>
<tr>
<td>Nurse</td>
<td>4</td>
<td>40%</td>
<td>22.2%</td>
</tr>
<tr>
<td>Psychologist</td>
<td>4</td>
<td>57.1%</td>
<td>11.1%</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
<td>50%</td>
<td>22.2%</td>
</tr>
</tbody>
</table>

Table 4: Referrers by professional group.

A summary of respondents' years of professional experience is given in table 5. The difference in years of professional experience between the referring and non-referring groups was not significant.

<table>
<thead>
<tr>
<th></th>
<th>Referrers</th>
<th>Non-referrers</th>
<th>Overall</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Years of professional experience</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>15.5</td>
<td>11.71</td>
<td>13.26</td>
<td>z (18, 26) = -1.77, p=0.077</td>
</tr>
<tr>
<td>Standard Deviation</td>
<td>6.9</td>
<td>10.4</td>
<td>9.23</td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>5 - 31</td>
<td>0.5 - 31</td>
<td>0.5 - 31</td>
<td></td>
</tr>
</tbody>
</table>

Table 5: Summary of respondents' years of professional experience

With regard to preferred model of working, a large proportion (n=18) of respondents ticked more than one box or described their approach as eclectic (table 6). Given the relatively small sample size involved in this study, it was not possible to examine further any relationship between specific therapeutic models and referral behaviour.
<table>
<thead>
<tr>
<th>Preferred model</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>CBT</td>
<td>10</td>
<td>22.7%</td>
</tr>
<tr>
<td>Counselling</td>
<td>9</td>
<td>20.5%</td>
</tr>
<tr>
<td>Psychodynamic</td>
<td>3</td>
<td>6.8%</td>
</tr>
<tr>
<td>Family/systemic</td>
<td>2</td>
<td>4.5%</td>
</tr>
<tr>
<td>More than one/eclectic</td>
<td>18</td>
<td>40.9%</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
<td>4.5%</td>
</tr>
</tbody>
</table>

Table 6: Preferred models of working.

The respondents rated how often they worked with specific mental health problems on 5-point scales (summarised in table 7). There was no significant difference between the referrer and non-referrer groups' mean rating of professional contact with any of the specified mental health problems.

<table>
<thead>
<tr>
<th>Mental Health Difficulty</th>
<th>Mean referrers ratings of contact</th>
<th>Mean non-referrers ratings of contact</th>
<th>Overall mean ratings of contact</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety</td>
<td>3.22</td>
<td>3.04</td>
<td>3.11</td>
</tr>
<tr>
<td>BPAD</td>
<td>3.5</td>
<td>3.73</td>
<td>3.64</td>
</tr>
<tr>
<td>Depression</td>
<td>3.83</td>
<td>3.65</td>
<td>3.73</td>
</tr>
<tr>
<td>OCD</td>
<td>2.39</td>
<td>2.31</td>
<td>2.34</td>
</tr>
<tr>
<td>Psychosis</td>
<td>4.33</td>
<td>4.42</td>
<td>4.39</td>
</tr>
<tr>
<td>Relationship/ Family</td>
<td>3.5</td>
<td>3.38</td>
<td>3.43</td>
</tr>
</tbody>
</table>

Table 7: Summary of ratings of time worked with specific mental health difficulties

Hypothesis (3) was therefore not supported.

Family Background

This optional section was completed by 36 (81.8%) of the respondents. Of the others, 5 (11.4%) completed some of the questions, omitting information about their age and gender. All gender and age data were therefore left out of the analysis. The remaining information is summarised in table 8.
<table>
<thead>
<tr>
<th></th>
<th>No. of respondents</th>
<th>No. in long term relationship</th>
<th>Mean no. of siblings</th>
<th>Mean no. of children</th>
</tr>
</thead>
<tbody>
<tr>
<td>Referrers</td>
<td>17</td>
<td>15</td>
<td>2.59</td>
<td>1.35</td>
</tr>
<tr>
<td>Non-referrers</td>
<td>24</td>
<td>14</td>
<td>1.83</td>
<td>1.09</td>
</tr>
<tr>
<td>Significance</td>
<td>N/A</td>
<td>Fishers exact</td>
<td>z (17, 24) = -1.742, p=0.079 (corrected sig level=0.0167)</td>
<td>z (17, 24) = -1.32, p=0.187 (corrected sig level=0.0167)</td>
</tr>
</tbody>
</table>

Table 8: Systemic background of referrers and non-referrers

There were no significant differences between the referrer and non-referrer groups in any of the data.

Discussion

Some of the results warrant further discussion. It was promising to note that none of the respondents stated they would not consider a referral to the family therapy service. Also, the proportion of respondents who knew about the family therapy service (90.9%) and the proportion that had referred (40.9%) compared favourably with a previous study (Gilleard, Lieberman & Peeler, 1992). This found that of a sample of local GPs, hospital doctors, district nurses and social workers, only 1/3 had heard of the family therapy clinic and just 22% had made a referral. This difference may reflect an increased awareness of systemic interventions within the Trust. However, it may also be due to the different work settings of the two samples. For example, the multi-disciplinary approach adopted by CMHTs may increase the likelihood of contact with a family therapist or a referral to family therapy services. Further research that encompasses health professionals from a broader range of settings is therefore needed.

With regard to hypothesis (1), neither the referring nor the non-referring group reported a mean understanding of systemic family therapy at or above the “quite good” level. However, the mean score of the referrer group was significantly larger. Both groups rated their mean level of training in systemic family therapy below the “moderate” level. The difference between them was not significant. This suggests that all respondents had similar perceptions about their level of training in systemic approaches. However, it would appear that those with a greater understanding of that training tended to refer to the family therapy service. An
investigation into what non-referrers do not understand about systemic approaches may be able to suggest ways in which training can be adapted.

There was no significant difference between referrers' and non-referrers' perceptions of systemic family therapy, so hypothesis (2) was not supported. This contrasts with previous research that reported perceptions had a big influence on referral behaviour (Gilleard, Lieberman & Peeler, 1992). This contrast could be due to sample bias, which will be discussed later. However, the particular perceptions measured in this study may also have influenced this result. Chadd and Svanberg (1994) looked at GPs' perceptions of clinical psychologists. These perceptions may not transfer well to CMHT health professionals' perceptions of systemic family therapy.

Although hypothesis (3) was not supported, the results did show that none of the referrer group had less than 5 years of experience. It could be that systemic approaches were considered by these mental health professionals in the early years of their career, but were not thought to be appropriate. However, it might also be the case that they did not know about or understand systemic family therapy when they completed their training. They therefore did not refer to systemic family therapy services until they accrued this knowledge and understanding through years of work. Further research into why this non-referral occurs may be useful.

There were no significant differences between the family backgrounds of referrers and non-referrers. However, because of the small numbers involved in the study, no firm conclusions can be drawn. The service may therefore wish to undertake further research in this area.

The study had a number of limitations, so the results need to be treated with caution. The experimental design chosen made it difficult to either test hypotheses (3) or explore any possible influence of family background on referral behaviour. Future research using the same design would need to define hypotheses about these in more precise terms. Alternatively, a qualitative approach using open-ended questions could be used. This might provide richer, more useful information. The small sample size and number of respondents also limited the study, as the data collected might not have been representative of the target population (e.g. respondents may have been more interested in systemic family therapy, thus biasing the results). Future studies could consider interviewing respondents or distributing questionnaires directly to them. However, issues of confidentiality would need to be
addressed. An alternative would be to send a second mailshot of questionnaires. Again, however, this would need non-respondents to be identified, which did not occur in this study in order to maintain confidentiality.

The results of this study have been fed back to the service (Appendix C). Given the limitations discussed, the results are best used as a platform for future research within the service. A number of areas where such research could focus were highlighted in the discussion.
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Leff, J., Vearnals, S., Brewin, C.R., Wolff, G., Alexander, B., Asen, E., Dayson, D., Jones, E., 
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family. In J. Byng-Hall & R. Whiffen (Eds.), Family therapy supervision. London: 
Academic Press.


McGoldrick (Eds.), The changing family life cycle: A framework for family therapy, second 

Clinical Psychology, 3, 35 – 36.
Appendix A

Questionnaire
Investigation into Health Professionals' Perceptions of Systemic Family Therapy

This study aims to look at how systemic family therapy is perceived by a range of health professionals. This information will help with future service planning, thus helping to better meet the needs of service-users. The study is anonymous and the data collected will be treated confidentially.

Thank you for contributing to this research study. If you have any questions or would like any feedback of results, please contact: Julian Morris, Psychology Department (PsychD), University of Surrey, Guildford, Surrey, GU2 7XH

This first section asks for information about your contact with and knowledge of systemic family therapy (please circle your responses).

1) Are you aware of the family therapy service?  
YES / NO

2) Do you know how to refer to the family therapy service?  
YES / NO

3) Have you ever referred to the family therapy service?  
YES / NO

   If yes, approximately how many times:
   1 2-5 More than 5
   If no, would you ever consider referring to family therapy?  
YES / NO

4) Please indicate on the scale below what you consider your level of understanding of systemic family therapy to be:

   1 None  2 Low  3 Moderate  4 Quite good  5 Very good

5) Please indicate on the scale below what you consider your level of training in systemic family therapy to be:

   1 None  2 Low  3 Moderate  4 Quite good  5 Very good
These next items ask about your perceptions of systemic family therapy. Please read the statements and indicate on the scales how much you agree or disagree with them by circling your responses.

6) Families can find systemic family therapy useful:

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly disagree</td>
<td>Disagree</td>
<td>Neither agree nor disagree</td>
<td>Agree</td>
<td>Strongly agree</td>
<td></td>
</tr>
</tbody>
</table>

7) Systemic family interventions are cost-effective:

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly disagree</td>
<td>Disagree</td>
<td>Neither agree nor disagree</td>
<td>Agree</td>
<td>Strongly agree</td>
<td></td>
</tr>
</tbody>
</table>

8) Practitioners of systemic family therapy are well trained:

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly disagree</td>
<td>Disagree</td>
<td>Neither agree nor disagree</td>
<td>Agree</td>
<td>Strongly agree</td>
<td></td>
</tr>
</tbody>
</table>

9) The use of systemic family interventions has a good evidence base:

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly disagree</td>
<td>Disagree</td>
<td>Neither agree nor disagree</td>
<td>Agree</td>
<td>Strongly agree</td>
<td></td>
</tr>
</tbody>
</table>

10) In general systemic family therapy interventions for mental health difficulties are effective:

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly disagree</td>
<td>Disagree</td>
<td>Neither agree nor disagree</td>
<td>Agree</td>
<td>Strongly agree</td>
<td></td>
</tr>
</tbody>
</table>

Please rate on the scales below how useful you think systemic family therapy is for each specific mental health problem (please circle your responses):

11) Anxiety Disorders:

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all useful</td>
<td>A little useful</td>
<td>Moderately useful</td>
<td>Quite useful</td>
<td>Very useful</td>
<td></td>
</tr>
</tbody>
</table>

12) Bi-polar Affective Disorder:

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all useful</td>
<td>A little useful</td>
<td>Moderately useful</td>
<td>Quite useful</td>
<td>Very useful</td>
<td></td>
</tr>
</tbody>
</table>
13) Depression:

<table>
<thead>
<tr>
<th></th>
<th>1 Not at all useful</th>
<th>2 A little useful</th>
<th>3 Moderately useful</th>
<th>4 Quite useful</th>
<th>5 Very useful</th>
</tr>
</thead>
</table>

14) Obsessive-Compulsive Disorder:

<table>
<thead>
<tr>
<th></th>
<th>1 Not at all useful</th>
<th>2 A little useful</th>
<th>3 Moderately useful</th>
<th>4 Quite useful</th>
<th>5 Very useful</th>
</tr>
</thead>
</table>

15) Psychosis:

<table>
<thead>
<tr>
<th></th>
<th>1 Not at all useful</th>
<th>2 A little useful</th>
<th>3 Moderately useful</th>
<th>4 Quite useful</th>
<th>5 Very useful</th>
</tr>
</thead>
</table>

16) Relationship / Family Difficulties:

<table>
<thead>
<tr>
<th></th>
<th>1 Not at all useful</th>
<th>2 A little useful</th>
<th>3 Moderately useful</th>
<th>4 Quite useful</th>
<th>5 Very useful</th>
</tr>
</thead>
</table>

Please list any other difficulties that you think family therapy would be useful for:

This section asks for information about your clinical work.

17) From the list below, please indicate your current profession by placing a tick:

- Counsellor
- Nurse
- Occupational Therapist
- Psychiatrist
- Psychologist
- Social Worker
- Other (please state)

18) How many years of professional experience do you have?

19) What setting do you work in at present (e.g. CMHT, primary care, in-patient etc.)?

20) From the list below, please indicate your preferred approach to working with clients (apart from medication) by placing a tick:

- Non-directive / counselling
- Cognitive / behavioural
- Psychodynamic
- Family / systemic
- Other (please state)
We would like to know more about the type of mental health problems you most often work with. Please rate on the scales below the level of professional contact you have with each specific difficulty (please circle your responses):

21) Anxiety Disorders:

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td></td>
<td></td>
<td>Low</td>
<td>Moderate</td>
<td>Quite high</td>
</tr>
</tbody>
</table>

22) Bi-polar affective disorder:

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td></td>
<td></td>
<td>Low</td>
<td>Moderate</td>
<td>Quite high</td>
</tr>
</tbody>
</table>

23) Depression:

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td></td>
<td></td>
<td>Low</td>
<td>Moderate</td>
<td>Quite high</td>
</tr>
</tbody>
</table>

24) Obsessive-Compulsive Disorder:

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td></td>
<td></td>
<td>Low</td>
<td>Moderate</td>
<td>Quite high</td>
</tr>
</tbody>
</table>

25) Psychosis:

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td></td>
<td></td>
<td>Low</td>
<td>Moderate</td>
<td>Quite high</td>
</tr>
</tbody>
</table>

26) Relationship / Family difficulties:

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td></td>
<td></td>
<td>Low</td>
<td>Moderate</td>
<td>Quite high</td>
</tr>
</tbody>
</table>

Please list any other difficulties that you regularly work with:

We are also interested in the relationship between an individual’s systemic background and their perceptions of systemic family therapy. This last section asks for systemic information. It is optional, but completing it would be very helpful for the study.

27) How many siblings do you have? 28) Are you in a long-term relationship?

----------------------

29) How many children do you have? 30) What is your age?

----------------------

31) What is your gender?

FEMALE / MALE

Thank you again for participating in this study.
Appendix B

Cover Letter
Dear Colleague,

We are currently undertaking a research project in order to inform future service planning for the XXX Family Therapy Clinic. Attached is a brief questionnaire (5-10 minutes) that is being distributed to a range of health professionals in a variety of settings across the Trust.

We are interested in your views. To help with this research, would you please complete the questionnaire and return it to XXX, your team secretary, from whom it will be collected.

If you have any questions about this research study, please contact,

XXX
c/o Psychology Department (PsychD)
University of Surrey
Guildford
Surrey
GU2 7XH

Thank you again for your involvement in this study,
Appendix C

Evidence of Feedback to Service
4 October 2001

Dear —

RE: Your Service Related Research Project

Thank you very much for feeding back today on your service related research project: "an initial study on referral patterns to systemic family therapy".

I have also discussed this with the Director of the Family Therapy Clinic, and we both felt this was a very interesting and useful study.

I was particularly intrigued by some of the results, particularly regarding the personal backgrounds of referrers. Perhaps this might be interesting enough to present at some point brief study for one of the journals?

Yours sincerely,

Consultant Psychologist
Major Research Project

An Investigation of Long-term Memory and Executive Functioning in Adults with Down's Syndrome

Completed in Year 3
Abstract

The concepts of multiple memory systems and the modularity of brain functioning offer a theoretical basis for the possible existence of specific cognitive strengths and weaknesses in different learning-disabled groups. Previous studies have highlighted an impairment in the verbal short-term memory of people with Down’s syndrome (DS), but there have been few studies exploring the long-term memory of this population. There also appear to be no studies of executive functioning in this group. A number of tests of long-term memory and executive functioning were therefore administered to a group of adults with DS (n=12) and a control group of adults with a learning disability of non-specific aetiology (n=16). The DS group performed significantly worse than the control group on three tests of verbal long-term memory. There was no significant difference between the two groups on a test of long-term visual memory. This pattern of results transferred to everyday memory tasks. Despite difficulties with the interpretation of some of the results, a specific weakness in the long-term retention and/or recall of verbal information in people with DS was specified from one of the memory tests. The DS group also performed significantly worse than the control group on one test of executive functioning. However, more research is needed before hypotheses about specific strengths and weaknesses in this area can be constructed. A number of implications for clinical practice and ideas for future research were suggested.

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1. Introduction

1.1 Overview

This study is concerned with the long-term memory and executive functioning of adults with Down's syndrome (DS). Long-term memory refers to our ability to encode, store and retrieve information and skills (Lezak, 1995). Executive functioning refers to cognitive processes that enable us to supervise, organise and control our behaviour (Stirling, 2002). These areas of cognitive ability therefore have a central role in our everyday lives. However, they have been little studied in the population of adults with DS (Pennington & Bennetto, 1998; Pulsifer, 1996).

This introduction will outline the concepts of long-term memory and executive functioning in greater detail, including a theoretical rationale for why they might be different in people with DS compared to other populations. It will then review previous research on the long-term memory and executive functioning of this group. Finally, the information will be drawn together to form hypotheses for investigating these cognitive domains in this study.

1.2 Neuropsychology and People with Learning Disabilities

1.2.1 General Learning Disabilities

Researchers interested in neuropsychology study a range of cognitive abilities, including general intelligence, memory, attention, perception and executive functioning (Lezak, 1995). Such research has largely focused on people with acquired cognitive disorders (i.e. cognitive disorders that result from brain damage that occurred in adulthood, such as head injury, stroke etc.). Results from these studies have furthered our understanding of normal brain functioning and informed clinical assessment and intervention strategies with people who have suffered such an injury (e.g. Lezak, 1995). In contrast, however, there has been relatively little neuropsychological research with people who have developmental cognitive disorders, which are more commonly known as learning disabilities (Burack, Hodapp & Zigler, 1988; Pennington & Bennetto, 1998).

The British Psychological Society (2001) has outlined three core criteria for a learning disability: significant impairment of a person’s intellectual functioning (e.g. IQ of below 70
on standardised intelligence assessments such as the Wechsler Adult Intelligence Scale, third edition; Wechsler, 1997); significant impairment of a person's adaptive/social functioning; and age of onset before adulthood. The major causes of learning disability include: heredity (about 5% of cases); early alterations of embryonic development, including chromosomal changes such as those that occur in DS (approximately 30% of cases); pregnancy and perinatal problems (approximately 10% of cases); general medical conditions acquired in infancy or childhood (approximately 5% of cases); and environmental influences and other mental disorders such as autism (approximately 15%-20% of cases). In addition, no aetiology can be identified in 30%-40% of cases (American Psychiatric Association, 1994).

Estimates of the number of people with a learning disability vary widely. However, one review suggested that between 810 000 and 2 100 000 people in the UK have some degree of learning disability (Emerson, Hatton, Felce & Murphy, 2001). Only a small proportion of this population have a profound, uniform impairment in all areas of cognitive functioning (1-2%; American Psychiatric Association, 1994). The rest of the population show relative strengths and weaknesses in specific cognitive abilities (Pulsifer, 1996).

Despite these differing causes and cognitive consequences of a learning disability, comparative research on the cognitive abilities of different learning-disabled groups is rare. Further, much of the research that has been carried out has focussed on children (Pulsifer, 1996). As such, our current understanding of the cognitive functioning of adults in different learning-disabled groups remains limited (Burack & Zigler, 1990; Carlesimo, Marotta & Vicari, 1996; Pennington & Bennetto, 1998).

1.22 Downs Syndrome (DS)

DS is the most common genetic cause of learning disability, with an incidence of approximately 1 in 600 (Bolton & Holland, 1994). It is caused by abnormalities on chromosome 21, but is not usually inherited. DS is associated with a number of physical characteristics, including microcephaly, slanting eyes and a broad neck. People with DS are also significantly shorter than those in the general population and about 50% of people with DS are classified in the obese range (Pulsifer, 1996).
In terms of cognitive functioning, people with DS are nearly all intellectually impaired. However, some individuals have IQs in the borderline or normal range. For example, one study reported that 9 out of 2748 institutionalised people with DS had IQs of 70 or over (Moore 1973; cited in Pulsifer, 1996). Compared to their general level of intellectual impairment, people with DS have a relative weakness in their expressive language skills (e.g. Sigman, 1999) and a relative strength in visuo-motor skills (e.g. Crnic & Pennington, 2000; Pulsifer, 1996; Wang, 1996). In addition, all adults with DS over the age of 40 who have had their brains studied post-mortem have been found to have neuropathology similar to that associated with dementia of the Alzheimer's type (e.g. Zigman, Schupf, Haveman & Silverman, 1997). There is also an increased risk of people with DS over the age of 40 developing the symptoms associated with this dementia (Holland, 1999), which include impairment of memory and executive functioning (American Psychiatric Association, 1994). Despite such findings, further investigation of the long-term memory and executive functioning abilities specific to adults with DS has been very limited (Pennington & Bennetto, 1998; Pulsifer, 1996).

1.3 Memory

1.3.1 Multiple Memory Systems

Why should there be a difference in the memory functioning of different populations, such as people with DS? Early theories of memory often regarded it as a single structure (Baddeley, 1995). People with a learning disability were therefore thought to have a globally impaired memory. Any research consequently used experimental groups that did not differentiate between aetiological groups (Simon, Agriesti & Rappaport, 1995).

The unitary view of memory changed in the 1960s, when theories were developed that incorporated different memory systems (e.g. Atkinson & Shiffrin, 1968). Although these initial theoretical models quickly ran into difficulties (Baddeley, 1995), the concept of different memory systems continued to influence later research. Current models of memory incorporate multiple separate memory systems (Nadel, 1994). These systems are differentiated in terms of the information they handle, the time over which they do this and the brain structures underlying them. They are thought to have evolved as special adaptions of information storage and retrieval for specific and functionally incompatible purposes. This has much in common with the theory of modularity of brain functioning (e.g. Fodor,
1983; cited in Stirling, 2002). This theory argues that cognitive functions are organised into distinct processing units (or modules). These modules are thought to be localised in different brain structures and to have evolved to deal with specific types of information. Therefore, although they collaborate with other modules to allow a particular task to be achieved (e.g. naming an object), they have a degree of specialisation and autonomy.

The concept of multiple memory systems based in different brain structures influences how the memory of different learning-disabled populations is understood. Neural dysfunction is not spread evenly throughout the brains of people with different clinical syndromes. Rather, different brain structures are impaired to varying degrees (Nadel, 1996). Therefore, if in a particular syndrome the brain structures that support some memory systems are impaired to a greater degree than others, performance on different memory tasks may vary. This provides a theoretical basis for the possibility of different memory strengths and weaknesses in different populations, including people with DS.

1.32 Measuring Memory Functioning

It is highly likely that different memory systems interact to influence performance on different memory tasks (Schacter & Tulving, 1994). Attempting to summarise all memory functioning by means of a single measure is therefore insufficient (Wang, 1996). In clinical practice, memory functioning is measured through self-reports, carer reports and an individual’s performance on standardised memory tests (Lezak, 1995). Memory performance is then typically summarised using a number of divisions of memory that have been developed. These are outlined below.

Historically, the first large-scale division of memory was between “short-term” and “long-term” memory. “Short-term” memory refers to the ability to retain information over short periods of time (of the order of seconds; Vallar & Papagno, 1995). It is transient and has limited capacity. The concept of short-term memory has itself been subdivided in one model, which is known as the “working memory” model (Baddeley & Hitch, 1974). Working memory consists of an alliance of temporary storage systems – an attentional system called the central executive that coordinates two “slave” sub-systems: the phonological loop (for verbal information) and the visuo-spatial sketchpad (for visual information).
"Long-term" memory refers to the ability to retain information over long periods of time. It has unlimited capacity and the potential to store information indefinitely (Lezak, 1995). Long-term memory has been sub-divided into a number of different measurable components. One such division is between implicit (or procedural) and explicit (or declarative) memory (Squire, 1987). Implicit memory refers to learned information contained within skills. It cannot, therefore, be consciously recalled as facts, data or events. In contrast, explicit memory refers to information, objects and events that are acquired through learning and so can be consciously recalled.

Another common division of memory differentiates between memory for verbal and visual information (e.g. Wilson, 1987). This refers to the modality by which the to-be-remembered information is presented (i.e. either verbal or visual information) and is applied to long-term memory, as well as the phonological loop and visuo-spatial sketchpad of working memory outlined above.

There are therefore a number of different divisions of memory performance that are measured. As standardised memory tests have developed, the functions that they measure have reflected these various divisions and sub-divisions (e.g. verbal long-term memory, visual long-term memory, verbal short-term memory, visual short-term memory). In recent years there has also been an increased interest in investigating memory in its natural context. This has been termed "everyday" memory (Cohen, 1996). Everyday memory is not a division of memory performance in the same way as long-term and short-term memory. In fact, everyday memory incorporates all these divisions. However, it differs in the way that it is measured. Rather than use abstract memory tests that aim to emulate laboratory conditions, everyday memory tests try to emulate real world situations. Everyday memory researchers argue that failures of memory are usual and there may be a difference between those that are seen as important by psychologists and those that occur in the real world (Cockburn, 1996). Laboratory findings may not therefore generalise into real world situations. This means that an ecologically valid assessment of memory functioning is as important as a carefully controlled laboratory assessment.

1.33 Previous Research on Memory in Adults with DS

Previous studies have reported that people with DS perform worse on tests of verbal short-term memory than tests of visual short-term memory (e.g. Marcell & Armstrong, 1982;
Marcell & Weeks, 1988; Wang & Bellugi, 1994). Jarrold and Baddeley (1997) explored such results further by investigating whether they were due to a deficit in overall verbal ability in DS rather than a memory deficit per se. They compared the performance of teenagers with DS (n=15; mean age=160 months) on tests of verbal and visual short-term memory with the performance of children with “moderate learning difficulties” (n=15; mean age=96.6 months) and mainstream developing children (n=15; mean age=58 months). All three groups were matched for verbal mental age. Verbal short-term memory was measured by a computerised digit span task in which participants had to recall a list of spoken numbers. This list increased in length as the test progressed. Visual short-term memory was measured by a computerised task in which participants had to recall a list of spatial positions. This list also increased in length as the test progressed. Despite the similar verbal abilities of the groups, there was a significant effect (p<0.01) of group and task. The DS group, unlike either of the control groups, showed poorer performance on the verbal short-term memory test than on the visual short-term memory test. In addition, there were no clear correlations between verbal ability and performance on the verbal short-term memory test. The authors also found no difference between the DS and control groups on a test of hearing ability, so this factor did not influence the result. It was therefore concluded that the poorer performance of the DS group was due to a deficit in verbal short-term memory rather than a deficit in general verbal ability.

Despite such reports of a specific deficit in the short-term verbal memory of people with DS, there have been only a limited number of studies investigating the long-term memory functioning of this population. In one of these few studies, Haxby (1989) investigated the age-related changes in a range of cognitive abilities in people with DS. He compared the performance of a group of young adults with DS (n=19; mean age=26 years), a group of older adults with DS and dementia (n=4; mean age=57 years) and a group of older adults with DS without dementia (n=5; mean age=46 years) on a number of cognitive assessments. This included two tasks aimed at measuring the ability of participants to commit new information to long-term memory. In the first task, participants had to recall which of three boxes an object had been hidden in at three intervals: immediately after the object had been hidden; after a ten second undistracted delay; and after a two minute distracted delay. In the second task participants had to recognise which of a number of geometric designs that were difficult to verbalise they had seen previously.
The group of older adults with DS without dementia performed significantly worse (p<0.01) than the younger adults with DS on the hidden object task. Not enough of the older adults with DS and dementia completed this task to allow statistical comparison. Both of the older adult groups (i.e. with and without dementia) performed significantly worse (p<0.001) than the group of younger adults with DS on the design recognition task. The author therefore concluded that as people with DS get older they become poorer at committing new information to long-term memory. However, the lack of a control group means this study cannot provide information about the relative memory performance of people with DS compared to other groups. In addition, the size of the older adult DS groups was very small, which makes it hard to draw conclusions about memory from between-group differences. This was compounded by the fact that one of the memory tasks was too difficult for many of the older adults with DS and dementia to complete.

Another study (Vicari, Belluci & Carlesimo, 2000) compared the performance of young adults with DS (n=14; mean age=21 years; mean mental age=6.5 years) and children without a learning disability matched for mental age (n=20; mean age=5.09 years; mean mental age=6.3 years) on tasks of implicit and explicit long-term memory. Implicit memory was assessed via four tasks: learning of a manual procedure; a serial reaction time task, a fragmented picture task, (i.e. at what level of detail can fragmented line drawings be identified and named); and a stem completion task in which participants were primed by a word-list before being asked to complete thirty word stems with the first word that came into their head. Explicit memory performance was also assessed via four tasks: word-list learning, in which a list of 12 words was repeated five times and participants were asked to recall as many words as possible after each presentation; word recognition, in which participants had to recognise which words spoken by the examiner had been presented 10 minutes earlier; picture recognition, in which participants had to identify pictures that they had been shown previously; and spatial sequences, in which participants had to recall the correct sequence in which an examiner had tapped a number of wooden blocks. There was no significant difference between the two groups on the implicit memory tasks, but the DS group performed significantly worse on all the explicit memory tasks (word-list learning, p<0.001; word recognition, p<0.05; picture recognition, p<0.01; spatial sequences, p<0.001). However, the use of a mentally aged matched control group of people without a learning disability means that it is unclear whether the results relate to all people with a learning disability or whether they are specific to the DS population. Further, the lack of a power analysis (see Cohen, 1988, for a full discussion of power analysis) means that the probability of a type II error (i.e.
not finding a significant effect when a real effect is in fact present) is unknown. This makes it difficult to interpret whether the absence of a significant difference in the performance of the two groups on the implicit memory tests was likely to be because the groups were of insufficient size.

A third study (Numminen, Service, Ahonen & Ruoppil, 2001) compared the performance of a group of adults with DS (n=15; mean age=41.8 years; mean mental age=5.03 years) and a group of adults with a learning disability of mixed aetiology matched for non-verbal intelligence (n=15; mean age=51.27 years; mean mental age=5.23 years) on tests of working memory and everyday memory. It was found that the DS group performed significantly worse (p<0.01) on all tests of phonological working memory. However, there was no significant difference between the two groups on any of the everyday memory measures used. This finding might indicate that any memory weaknesses in people with DS do not translate to everyday situations. However, the results of this study are difficult to interpret because of the age of the DS group, which ranged from 38-48 years old. As outlined earlier, in post mortem studies all adults with DS over the age of 40 years have been found to have neuropathology similar to that found in people with dementia of the Alzheimer’s Type (e.g. Zigman, Schupf, Haveman & Silverman, 1997). This dementia is associated with significant cognitive decline (American Psychiatric Association, 1994). The performance of this experimental group may therefore have been affected by the presence of this underlying neuropathology.

1.34 Limitations of Previous Research on Memory in Adults with DS

Patterns may be beginning to emerge from the results of the previous studies outlined above. The explicit long-term memory performance of adults with DS seems to worsen with age and adults with DS appear to have a relative weakness on tasks that rely heavily on verbal short-term memory. There is also a suggestion that adults with DS perform comparably to other groups of similar cognitive ability on everyday memory tasks, tasks that rely heavily upon visual short-term memory and implicit memory tasks. However, these suggestions are only tentative, as a number of methodological issues make it difficult to interpret these studies as a group.

Firstly, the studies used different control groups (either mentally aged matched children without a learning disability or adults with a learning disability of different aetiology) or no
control group at all. This is problematic because different types of control group provide different information about the experimental population. Use of a mentally aged matched control group of children provides information about whether a relative developmental deficit is present. However, it does not provide information as to whether any strengths or weaknesses are specific to the DS population, or whether they apply to all people with a learning disability. A learning-disabled control group is needed for this and what is lacking in the literature is such comparative research between different learning-disabled groups (Burack & Zigler, 1990; Carlesimo, Marotta & Vicari, 1996; Pennington & Bennetto, 1998; Pulsifer, 1996; Simon, Agriesti & Rappaport, 1995).

A second methodological issue when trying to interpret the above studies as a group is that they used experimental groups of adults with DS with different age ranges, which included both younger and older adults. As the memory performance of people with DS changes across the lifespan (e.g. Haxby, 1989), it is difficult to directly compare the results of the different studies. The inclusion of adults with DS over the age of 40 years in any study also has specific problems due to the possible presence of neuropathology associated with dementia of the Alzheimer's type (as outlined previously).

A third difficulty with these studies is that there was little use of formal measures. Although there are difficulties in using such measures in research with people with a learning disability (e.g. Dalton & Wisniweski, 1990), many are used in clinical practice with this population. If some of these measures could be used for research purposes, it would facilitate both replication of results through use of a standardised procedure and comparison between different groups across different studies.

1.4 Executive Functioning

1.4.1 Different Executive Functioning in Different Populations?

As stated earlier, the term "executive functioning" refers to the cognitive skills that enable us to supervise, control and organise our behaviour (Stirling, 2002). Lezak (1995) identified four broad categories of executive functions: volition, planning, executing activities and self-monitoring. "Volition" refers to a person's motivation to act. It involves appreciating personal and social needs and initiating activity to meet those needs. "Planning" refers to the ability to form strategies to attain an objective. "Executing activities" refers to the ability to
engage in purposeful action. This includes initiating, modifying and stopping behaviours as appropriate to the situation. It also refers to the ability to persist with lengthy or complex tasks. “Self-monitoring” refers to the ability to spontaneously monitor and self-correct behaviour, including avoiding perseverative responses and careless errors. These definitions highlight the importance of executive functions in allowing us to engage in independent, self-serving and purposeful behaviour (Lezak, 1995).

Why should there be a difference in the executive functioning of different populations? Historically, executive functions were thought to be associated with the frontal lobes of the brain. However, this perception has changed in recent years as executive functioning deficits have been reported in people with injuries in other brain areas (Spreen & Strauss, 1998; Stern & Prohaska, 1996). Nevertheless, as with memory, executive functioning refers to cognitive abilities that are assumed to be based upon underlying brain structures (Lezak, 1995). If the principle of modularity (outlined in section 1.31) is adopted then different underlying brain structures can be impaired to different degrees. This could, therefore, result in different executive functioning abilities in different groups, including people with DS.

1.42 Measuring Executive Functions

Impaired executive functions have a major impact upon day-to-day living (Lezak, 1995). They are therefore an important part of neuropsychological assessment (Spreen & Strauss, 1998). However, there are difficulties in completing such assessments. Firstly, impairment of executive functions does not result in a single syndrome of behaviours (Stern & Prohaska, 1996). Different executive functions can be impaired to different degrees and this can occur independently of impairment of general intelligence (Kolb & Whishaw, 1996). This means that executive deficits can go undetected by standard measures. Secondly, the executive functions are themselves poorly defined, which can lead to difficulties identifying what is being measured and discriminating it from other cognitive abilities (e.g. Pennington, 1997; Wilding, Cornish & Munir, 2002). Thirdly, executive functioning tests may not be sensitive to executive functioning impairments because such tests are not analogies of everyday situations. An individual may therefore have difficulties in everyday life due to executive deficits, yet still perform well on tests of executive functioning because they are structured tasks.
Despite these difficulties, a number of measures of executive functioning have been developed. These are frequently used by neuropsychologists in clinical practice and are often chosen for their face validity (Lezak, 1995; Spreen & Strauss, 1998).

1.43 Previous Research on Executive Functioning in the DS Population

Reviews of the research literature on the cognitive functioning of the DS population have highlighted the lack of research on the executive functioning of this group (Pennington & Bennetto, 1998; Pulsifer, 1996). A literature search by the present author using the PsychInfo search engine (search terms “Down* syndrome* AND “executive* function*”) resulted in only six studies being identified. Five of these were studies that had used children with DS as a control group (Munir, Cornish & Wilding, 2000; Piven & Palmer, 1997; Ruble, 2001; Ruble & Scott, 2002; Wilding, Cornish & Munir, 2002). For example, Wilding, Cornish and Munir (2002) investigated the executive functioning of children with fragile-X syndrome (fragile-X syndrome is the most common known cause of inherited learning disability; for a review see Pennington & Bennetto, 1998). Their study compared the performance of a group of boys with fragile-X syndrome (n=25, mean age=10.88 years), a group of boys with DS matched for mental and chronological age (n=25; mean age=11.17 years) and a group of boys without a learning disability matched for mental age (n=50; mean age=7.78 years) on a task which involved them clicking on different targets on a computer screen. On a part of the task that required the participants to switch between clicking alternate targets, the fragile-X group was significantly worse (p<0.0001) than the DS group. Further, both the fragile-X group and DS group were significantly worse (p<0.0001) at switching attention than the group of children without a learning disability. These results suggest that children with DS may have a deficit in some areas of executive functioning (e.g. modifying behaviour, stopping perseverative responses) compared to the non learning-disabled population. However, they do not identify whether this is a weakness relative to people with a learning disability without fragile-X syndrome. Studies that use people with DS as a control group therefore tell us little specific information about the DS population.

The sixth study from the present author’s literature search was a case study of a 30-year-old woman with DS (Papagno & Vallar, 2001). This study included some assessment of the woman’s executive functions. On a verbal fluency task, which required her to produce as many words as she could that began with a given letter (“F”, “P” or “L”), she performed at the lower end of the normal range. On a task that required her to simultaneously complete
both a digit span (repeating a string of numbers) and tracking task (crossing out boxes on a page), she also performed in the normal range. However, she was unable to complete a card-sorting task. The authors concluded that the woman was impaired in some areas of executive functioning. However, this was a case study comparing the performance of one woman with DS with norms based on the general population. In addition, the authors reported that the woman studied was of interest partly because her linguistic skills were unusually good for a person with DS. There is therefore no basis for generalising these results to other members of the DS population.

This author could therefore identify no previous research that had the specific aim of investigating the executive functions of adults with DS. Although it may be possible to draw some tentative hypotheses about the executive functioning of this group from the studies outlined above, it is clear that further research in this area is needed.

1.5 Clinical Implications

Further investigation of the long-term memory and executive functioning of adults with DS would not simply be an academic exercise. Results could have implications for clinical work with the DS population. For example, there are a number of strategies that are used in rehabilitation work with people who have cognitive deficits following a brain injury (e.g. Johnstone & Stonnington, 2001). These include techniques for helping people minimise the impact of impairments in visual memory, verbal memory and/or executive functioning. Knowledge of any strengths or weaknesses in these cognitive areas in the DS population would suggest similar rehabilitation techniques should be used with them in educational, occupational and clinical settings. Such techniques could help people with DS make choices and promote their independence. This is consistent with key principles in the “Valuing People” White Paper (Department of Health, 2001), the government’s strategy for people with learning disabilities.

Another clinical implication could be for the assessment of older adults with DS who may be suffering from dementia. This assessment currently occurs primarily through caregiver reports and clinical evaluations/observations (Crayton & Oliver, 1993). However, these approaches may miss the early changes that occur in dementia of the Alzheimer’s type, which involve memory and executive functioning deficits. Cognitive assessment may be better placed to detect the early and often subtle cognitive impairments. However, such assessment
occurs in the context of varying degrees of pre-existing intellectual impairments (Crayton & Oliver, 1993). A clearer understanding of the typical pattern of impairments found in people with DS could help this process and quicken the diagnosis of dementia. This will become increasingly important if pharmacological interventions that help slow the progression of dementia of the Alzheimer’s type (e.g. Donepezil; National Institute for Clinical Excellence, 2001) are approved for use with the DS population.

Knowledge of strengths and weaknesses in long-term memory and executive functioning could also have implications for clinical formulation with people with DS. In people with an acquired brain injury, neuropsychological deficits can be associated with challenging behaviour (e.g. Lezak, 1995). An understanding of an individual’s cognitive strengths and weaknesses should therefore be an important part of the conceptualisation of challenging behaviour in people with learning disabilities as well (e.g. Emerson, 1995). This knowledge could inform intervention strategies as well as providing greater understanding of the context in which such behaviour is occurring.

1.6 Aims of the Present Study

1.61 Summary

This introduction has highlighted the importance of long-term memory and executive functioning in our ability to engage in day-to-day activities. The concepts of multiple memory systems and the modularity of brain functioning offer a theoretical basis for the possible existence of specific cognitive strengths and weaknesses in these cognitive domains in adults with DS. However, previous research in these areas has been very limited. Further, methodological differences make it hard to directly compare and interpret the results of the few studies that have been carried out.

1.62 Research Questions

This study will investigate long-term memory and executive functioning in adults with DS by addressing the following research questions:

i) Are there specific strengths and weaknesses in the explicit long-term memory of adults with DS?
ii) Are there specific strengths and weaknesses in the executive functioning of adults with DS?

To achieve this, a number of tests of verbal and visual long-term memory and executive functioning will be administered to a group of adults with DS. The study will differ from previous research in that these tests will have standardised procedures, which will facilitate replication of the results and comparison with future studies. In addition, a control group of adults with a learning disability of non-specific aetiology (matched for age and general level of intelligence) will be used to identify the strengths and weaknesses specific to people with DS. Further, the DS group will be under 40 years of age to minimise any influence from the neuopathology found in DS adults above this age.

Previous research has suggested that adults with DS have a specific deficit in verbal short-term memory, but not in visual short-term memory (e.g. Jarrold & Baddeley, 1997; Marcell & Armstrong, 1982; Marcell & Weeks, 1988; Wang & Bellugi, 1994). This study will hypothesise that a similar difference will occur in the explicit long-term memory of this group. Another study found no difference between the performance of adults with DS and adults with a learning disability of mixed aetiology on everyday memory tasks (Numminen, Service, Ahonen & Ruoppil, 2001). In line with this finding, the present study will hypothesise that there will be no significant difference between adults with DS and learning disabled controls on an assessment of verbal and visual long-term and short-term memory via tasks that are analogous to everyday situations. The present study will also hypothesise that there will be a difference in the performance of adults with DS and learning disabled controls on tests of executive functioning. However, the lack of previous research means that no direction will be indicated in this hypothesis.

1.7 Hypotheses

1) Adults with DS will perform significantly worse on assessments of verbal long-term memory than adults with a learning disability of non-specific aetiology.

2) There will be no significant difference in performance on assessments of visual long-term memory between adults with DS and adults with a learning disability of non-specific aetiology.
3) There will be no significant difference in performance on assessments of everyday memory between adults with DS and adults with a learning disability of non-specific aetiology.

4) There will be a significant difference in performance on assessments of executive functioning between adults with DS and adults with a learning disability of non-specific aetiology.
2. Method

2.1 Design

The study used an “independent groups” design, comparing the performance of an experimental group and control group on tests of long-term memory and executive functioning. The required sample size was calculated using a power analysis computer program (GPOWER; Erdfelder, Faul & Buchner, 1996). The power of a study is the likelihood that it will detect an effect that is actually present (i.e. the probability of avoiding a type II error; Breakwell, Hammond & Fife-Schaw, 2000). Despite its importance, power has often been ignored in previous research (Cohen, 1992; 1988). For this study, an a-priori power analysis reported that for a power of 0.7, the study would need a sample size of 32 (assuming a large effect size of 0.8 and a significance level of 0.05). The aim was therefore to recruit two groups of 16 people.

2.2 Participants

2.2.1 Experimental Group

Twelve adults with DS were recruited to the experimental group. Demographic information is provided below in table 1. People were excluded from the study if:

- they had already taken part in a number of research studies.
- they had significant visual difficulties (this could have impaired their ability to view some of the test materials).
- they had significant hearing difficulties (this could have impaired their ability to complete tests that required listening to and recalling verbal items).
- they had autism (autistic people often have difficulties with the comprehension and expression of verbal concepts, which could have put them at a disadvantage in some of the tests; see Pennington & Bennetto, 1998, for a review of autism).
- English was not their first language or if they did not use speech as their main means of communication (a number of the tests required the participants to listen to verbal items and respond verbally).
- they had a severe physical disability (some of the tests required participants to manipulate shapes or use a pencil).
they had a currently diagnosed severe mental health problem, had undergone a recent change in medication or were known to be abusing substances such as alcohol or other drugs (these factors could have impaired their performance on the tests).

- they were not between the ages of 18-40 (in post mortem studies all adults with DS over the age of 40 have been found to have brain pathology similar to that seen in older adults with dementia of the Alzheimer’s type (e.g. Zigman, Schupf, Haveman & Silverman, 1997). This pathology is thought to affect memory, which could impair performance on the tests).

2.22 Control Group

Sixteen adults with a learning disability of non-specific aetiology were recruited to the control group. Demographic information is provided below in table 1. Most of the exclusion criteria were the same as those listed above. However, the age range of the control group was more varied than that of the experimental group, as the association with dementia of the Alzheimer’s type neuropathology is specific to people with DS. The mean age of both groups was still in the 18-40 years range.

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<thead>
<tr>
<th>Group</th>
<th>Total number</th>
<th>Males</th>
<th>Females</th>
<th>Mean age (SD)</th>
<th>Age Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>DS</td>
<td>12</td>
<td>7</td>
<td>5</td>
<td>32.58 years (5.87)</td>
<td>23-40 years</td>
</tr>
<tr>
<td>Control</td>
<td>16</td>
<td>6</td>
<td>10</td>
<td>40.38 years (8.92)</td>
<td>25-56 years</td>
</tr>
<tr>
<td>Total Sample</td>
<td>28</td>
<td>13</td>
<td>15</td>
<td>37.04 years (8.58)</td>
<td>23-56 years</td>
</tr>
</tbody>
</table>

Table 1: Participants' demographic information

2.3 Measures

2.3.1 Test Selection

The tests selected needed to measure: verbal long-term memory; visual long-term memory; executive functioning; everyday memory. A measure of general intelligence was also required to compare the two groups’ level of functioning. As outlined in the introduction, some weaknesses in the language skills of people with DS have been identified (e.g. Sigman, 1999). It was therefore important to consider the verbal ability of the two groups when interpreting test results, so a measure of verbal ability was selected. Previous studies have also highlighted that adults with DS have a specific weakness in short-term verbal memory (e.g. Jarrold & Baddeley, 1997; Marcell & Armstrong, 1982; Marcell & Weeks, 1988; Wang
& Bellugi, 1994). To investigate if this result was consistent for the groups in this study, measures of verbal and visual short-term memory were administered.

Identifying measures that were appropriate for this study was problematic. Many psychological tests used with the general population are not suitable for use with people with a learning disability, for reasons including: people with a learning disability perform at floor level on many tests; the language used is difficult for people with a learning disability to understand; and there is a lack of normative data for the learning disabled population (Dalton & Wisniweski, 1990). However, strategies to work around these difficulties have been identified and used. These include: adapting standard neuropsychological tests; using tests developed for assessing children; and using tests developed specifically for assessing people with intellectual impairments (Crayton, Oliver, Holland, Bradbury & Hall, 1998).

The selection of measures for use in this study was discussed with a clinical psychologist with experience in the fields of learning disabilities and neuropsychology. This discussion included consideration of the test instructions, the availability of normative data, reliability, validity and the possibility of obtaining floor effects. The following tests were chosen.

**Verbal Memory**

1) “Adult Memory and Information Processing Battery” (AMIPB; Coughlan & Hollows, 1984)

The AMIPB is a standardised battery used to assess memory and information-processing skills. It consists of a number of tests of memory and information processing that can be used together or individually. It includes two memory sub-tests that involve verbal presentation of stimuli and verbal recall (“Story Recall” and “Word-list Learning”), which measure both short-term and long-term memory. In Story Recall, the participant is read a short story and asked to recall as much of it as possible both immediately after presentation and after a 30-minute delay. In Word-list Learning the participant is read a list of words five times. After each presentation of the list, the participant has to recall as many of the words as possible in any order. After the five presentations a different word-list is read out once only as an interference task. The participant is asked to recall as many words as possible from this list. They are then asked to recall as much of the first list as possible, without it being represented.
The AMIPB manual provides standardisation, reliability and validity data for the different sub-tests (Coughlan & Hollows, 1984). The standardisation sample did not include people with IQs in the learning disabled range. However, it did include a validation study assessing sensitivity to cerebral dysfunction in people who had suffered severe head injuries. This group demonstrated significant memory impairment. This application of the test suggests it can be used with impaired populations without achieving floor effects. The instructions of these two sub-tests are also simple, minimising the effect of language. The Word-list Learning and Story Recall sub-tests were therefore selected as measures of short-term and long-term verbal memory in this study.

Visual Long-term Memory

2) “The Doors and People Test” (DPT; Baddeley, Emslie & Nimmo-Smith, 1994)

The DPT consists of a number of tests that assess long-term explicit memory (Baddeley, Emslie & Nimmo-Smith, 1994). Although most of these tests are too difficult for many people with a learning disability, the DPT sub-tests can also be used individually. Doors A was considered to be appropriate for this population. It is the easiest test in the visual battery, as it has more obvious differences between distraction items and the to-be-remembered stimuli. In Doors A, participants are first presented with 12 pictures of doors. They are then shown twelve further pages, each of which has four pictures of doors including one shown in the first presentation. The participant is required to pick out those doors that they have been shown previously.

Neither reliability information nor validation studies for people with learning disabilities are reported in the DPT manual (Baddeley, Emslie & Nimmo-Smith, 1994). However, the instructions for Doors A are simple and practice items are provided, minimising the effects of poor language skills. The DPT has been shown to be highly consistent with other measures of memory function (Hunkin et al., 2000). It has also discriminated between controls and people with dementia of the Alzheimer's type (Greene, Baddeley & Hodges, 1996) and people who have had either a left or right temporal lobectomy (Morris, Abrahams, Baddeley & Polkey, 1995). Further, the Doors A sub-test did not have floor effects with these populations. These results suggest that it is a valid measure for discriminating impaired memory performance. Doors A was therefore selected as a measure of long-term visual memory for use in the present study.
Visual Short-term Memory

3) "Cognitive Ability Test to Assess Dementia in People with Down Syndrome" (CAT; Crayton, Oliver, Holland, Bradbury & Hall, 1998)

The CAT was developed to meet a clinical need. It is used, as its title suggests, to help in the assessment of dementia in people with Down’s syndrome. It comprises a number of sub-tests of cognitive and behavioural functioning, two of which are useful for investigating visual short-term memory ("Object Memory" and "Picture Memory").

In Object Memory, participants are presented with between two and six objects (e.g. watch, key, purse). On each presentation, the participant looks at the objects before closing their eyes. The assessor then covers one of the objects. The participant is asked to open their eyes and recall which item has been covered. The number of objects increases with every second presentation, up to a maximum of 6 (i.e. two objects on the first and second presentations, three objects on the third and fourth presentations and so on). The Picture Memory sub-test is the same as Object Memory, except that the participant is presented with pictures (e.g. football, lamp, mug) instead of objects. A score of one point is given for an object/picture correctly recalled.

The CAT has a standardised procedure, but there are no substantial research data on the Picture and Object Memory sub-tests. However, the instructions are very simple and these tests have good face validity. A combination of the Picture and Object Memory scores was therefore used in the present study to give a measure of visual short-term memory.

Everyday Memory

4) "Rivermead Behavioural Memory Test for Children" (RBMT-C; Wilson, Ivani-Chalian & Aldrich, 1991)

The RBMT-C was developed from the original Rivermead Behavioural Memory Test (Wilson, Cockburn & Baddeley, 1985). A number of authors have highlighted the ecological validity of these two assessments (e.g. Baddeley, 1995; Cockburn, 1996; Cohen, 1996; Wilson & Ivani-Chalian, 1995; Wilson, Ivani-Chalian, Besag & Bryant, 1993). Both these tests measure memory through a variety of everyday tasks. This includes tasks that rely primarily on verbal long-term memory ("Delayed Prose Recall"), visual long-term memory ("Picture Recognition", "Face Recognition" and "Route Delayed"), verbal short-term memory
Immediate Prose Recall”) and visual short-term memory (“Route Immediate”). The other RBMT-C tasks rely primarily on prospective memory (memory for intentions and plans; “Belonging”, Appointment”, “Message Immediate” and “Message Delayed”), cued verbal long-term memory (“Name Learning”) and memory for orientating information such as day, time and place (“Orientation”).

Wilson and colleagues reported on the validity and reliability of the RBMT-C as a test of memory (Wilson, Ivani-Chalian, Besag & Bryant, 1993). They also demonstrated the validity of the RBMT-C as a test of everyday memory by finding good correlation between children’s results on the test and parents’ reports of their children’s everyday memory failures. In addition, the RBMT-C has been evaluated as a useful measure of memory functioning in adults with DS (Hon, Huppert, Holland & Watson, 1998). Normative data have not yet been produced for the learning disabled population so total scores cannot be calculated. However, comparisons can be made based on the raw scores of individual sub-tests (Hon, Huppert, Holland & Watson, 1998; Numminen, Service, Ahonen & Ruoppila, 2001; Spreen & Strauss, 1998). The RBMT-C was therefore selected as a measure of everyday memory for use in the present study.

Executive Functioning

5) “Weigl Color-Form Sorting Test” (CFST; Goldstein & Scheerer, 1941)

The CFST assesses the ability to form abstract concepts and switch cognitive set, two abilities grouped under executive functioning. Participants are required to sort 12 coloured shapes into groups “that go together” (i.e. according to shape or colour). Once this is completed they are asked to sort the shapes in a different way. Ability to do this, and whether this was prompted or unprompted, is recorded and converted to a score.

The CFST measures similar skills to the Wisconsin Card Sorting Test (WCST; Heaton, Chelune, Talley, Kay & Curtis, 1993), which is widely used as an assessment of executive functions (Spreen & Strauss, 1998). However, the WCST is long and complex, making it unsuitable for the learning disabled population. In contrast, the instructions of the CFST appear simple, which should limit the effects of poor language skills. This author could find no reliability information or studies that used the CFST with people with learning disabilities. However, the CFST has good face validity as a measure of cognitive flexibility. Criterion validity was demonstrated in two studies that found people with organic brain damage
performed significantly worse on the CFST than controls (Byrne, Bucks & Cuerden, 1998; Grewal & Hayward, 1984). These studies also provide a quantitative scoring system. The CFST was therefore considered to be appropriate for use in the present study as a measure of executive functioning.

6) “Cognitive Ability Test to Assess Dementia in People with Down Syndrome” (CAT; Crayton, Oliver, Holland, Bradbury & Hall, 1998)

The CAT includes a simple card-sorting task. Participants are given a shuffled pack of 52 cards, 26 of which are white and 26 of which are black. They are then timed as they sort the cards into two separate piles according to colour. As such it measures motor speed, processing speed and the ability to maintain cognitive set.

The instructions for this task are simple, minimising the effect of any language impairment. No floor effects were reported in a study assessing the value of the CAT for clinical use with the DS population (Crayton, Oliver, Holland, Bradbury & Hall, 1998). No reliability or validity information was available. However, due to the simplicity of this task it was included in the study as a measure of executive functioning.

7) “Color Trails Test” (CTT; D’Elia & Satz, 1996)

The Trail-Making Tests (TMT; Reitan & Wolfson, 1993) are widely used in neuropsychological settings to assess speed of information processing, ability to divide attention and cognitive flexibility, which are executive functions. There are two parts to the TMT. In the first part, participants are presented with a page on which 25 circles are arranged. Each circle contains a number from 1-25. Participants are timed as they draw a line that connects these circles in numerical order (i.e. 1-2-3 etc.). Number of errors and time taken are compared to normative data to give a measure of speed of information processing. In the second part of the TMT participants are again timed as they draw a line that joins circles arranged on a page. However, this time the circles contain either a number or a letter. When connecting the circles, the participant must alternate between numbers and letters in correct numerical and alphabetical order (i.e. 1-A-2-B-3-C etc.). Number of errors and time taken are again compared with normative data to provide a measure of cognitive flexibility and ability to divide attention.
The Trail-Making Tests require a participant to be able to read both numbers and letters of the alphabet. This is difficult for many learning disabled people. However, the CTT provides a comparable alternative to the TMT that only requires the participant to be able to read numbers and discriminate between two colours. Part one of the test is the same as the TMT. However, rather than alternating between numbers and letters on part two of the test, participants instead alternate between different coloured circles (i.e. 1 in a pink circle, 2 in a yellow circle, 3 in a pink circle, 4 in a yellow circle etc.). Scoring is the same as with the TMT.

The CTT manual provides norms and test-retest reliability figures (part one, $r=0.644$; part two, $r=0.787$; 100% agreement of clinical interpretation across the test-retest conditions). Additional studies are also reported that demonstrate the CTT's validity and correlation with the TMT (e.g. Maj et al., 1993, 1994; Williams et al., 1995). The CTT has not been standardised on the learning disabled population. However, it was designed as a culture-fair assessment tool that minimises the effects of language (D'Elia & Satz, 1996). The CTT was therefore selected as a measure of executive functioning.

8) Tests of Verbal Fluency

Tests of verbal fluency have been widely used to measure word initiation, the ability to maintain set and interference control, which are executive functions (Lezak, 1995). The participant is asked to provide as many words as possible that either begin with a certain letter or belong in a particular category (e.g. animals) within a given time period (e.g. 60 seconds).

Spreen and Strauss (1998) reviewed a large number of studies demonstrating the reliability and validity of verbal fluency tests (e.g. Cahn et al., 1995; Des Rosiers & Kavanagh, 1987; Mutchnick et al., 1991). Normative data are also provided in this review (from Tombaugh, Kozak & Rees, 1996). The category versions of the verbal fluency test (VFC) are considered easier (Spreen & Strauss, 1998) and so may be more suitable for the learning disabled population. The number of correct responses given by participants is their score, so floor effects are rare, and the simple instructions minimise the effect of poor language skills. A VFC test that required participants to name as many different animals as they could in 60 seconds was therefore chosen for use in the present study as a measure of executive functioning.
General Intelligence

9) “Ravens Coloured Progressive Matrices” (RCPM; Raven, 1956)

The RCPM, Standard (Raven, 1996) and Advanced Progressive Matrices (Raven, 1994) are considered to be relatively culture-fair measures of “pure” non-verbal intelligence (e.g. Carpenter, Just & Shell, 1990). They provide information on a person’s ability to form new, largely non-verbal, insights (Raven, 1956). Participants are presented with 36 coloured patterns, one after the other, each of which has a piece missing. They are required to identify which one of six choices is the piece that most appropriately completes the pattern. The simple instructions and non-verbal nature of this test minimise the effect of a participant’s language abilities.

The RCPM was designed for use with a range of populations, including people with learning disabilities. Its manual (Raven, Court & Raven, 1990) reports good test re-test reliability (r=0.85-0.92) for different developmental groups. Further reliability and validity studies are discussed by Spreen and Strauss (1998). Although normative data are only provided for children, conversion tables in the test manual allow RCPM scores to be converted to a Standard Matrices score and consequently the equivalent mental age. Previous research has also made comparisons of learning disabled groups on the basis of RCPM raw scores (Numminen, Service, Ahonen & Ruoppil, 2001). The RCPM was therefore selected as a measure of general intelligence for matching the experimental and control groups in the present study.

Verbal Ability

10) “British Picture Vocabulary Scale, Second Edition” (BPVS-II; Dunn, Dunn, Whetton, & Burley, 1997)

The BPVS-II is a test of English hearing vocabulary. Participants are shown a number of pages, each of which has four pictures on it. For each page, the assessor reads out a word and the participant is required to point to the picture that is most representative of that word.

The BPVS-II was designed for use with a number of different populations and age ranges, including people with learning disabilities. Its items therefore range in difficulty and floor effects are unlikely. Further, the simple test instructions minimise the effect of any poor language skills. The test manual (Dunn, Dunn, Whetton, & Burley, 1997) provides norms
and standardisation information. It also demonstrates the test’s criterion and content validity and reports good split-half reliability \( (r=0.86) \). The BPVS-II was therefore used to compare the verbal ability of the experimental and control groups in the present study.

### 2.4 Procedure

#### 2.4.1 Setting

The study was carried out in a large region covered by a single NHS Trust. Participants were selected from the learning disabled population in this region (procedure outlined below).

#### 2.4.2 Ethical Approval

The study was granted approval by the relevant ethics committees and NHS Trust Research and Development steering group prior to commencement (approval letters in appendix A).

#### 2.4.3 Recruitment

A letter was sent to Clinical Psychologists (appendix B) and the managers of residential and day service providers for people with learning disabilities (appendix C) within the region. The letter asked Clinical Psychologists and managers to briefly explain the study to those users of their services that met the study criteria and ask if they were willing to speak to a researcher. In this way, only the names of those people that agreed to speak to a researcher were then passed on, thus maintaining confidentiality. The letter was followed up via a telephone call shortly after it was sent. A sheet providing further information about the study was provided (appendix D), and the researcher was available to provide more details and answer any questions if required.

The researcher visited those people who agreed to discuss the study further. In this meeting potential participants were supplied with an information sheet (appendix E) and the study was explained in detail. Other information sheets were also available for advocates, keyworkers and parents (appendix F). This allowed those who were interested in participating in the research study to discuss it with others before giving consent.
Ensuring that participants give informed consent when joining a research project is as important as ensuring patients have given informed consent for treatment (Department of Health, 2001). The British Psychological Society (2000) has also stated that, “Where possible, the real consent of ... adults with impairments in understanding or communication should be obtained” (p.9).

Obtaining informed consent from people with learning disabilities is problematic, due to their difficulties with understanding and increased likelihood of acquiescence (e.g. Finlay & Lyons, 2002). There has also been relatively little research in this area. However, one set of criteria has been outlined (Arscott, Dagnan & Kroese, 1998). These criteria highlight questions that can be used to assess the extent to which an individual is giving their informed consent to participate in research. These questions were adapted for use in this study:

i) What will we be doing together?
ii) How long will it take?
iii) What are the good things about taking part?
iv) What can you do if you decide you don’t want to take part any more?

A specific procedure for consent was therefore followed. After the study was explained to a potential participant and he/she had been provided with the relevant information sheets (appendices E, F), the above four questions were asked. If the person could not answer all of them, information about relevant key areas was provided again. The questions were then repeated, up to five times if necessary. If an individual could still not answer all the questions, or there were any doubts about their capacity to consent, they were not included in the study. In total, six people were excluded from the study at this stage.

Once a person had answered all the questions, they completed a consent form with the researcher. Local Research Ethics Committees now provide a standard consent form (appendix G). However, this form is inappropriate for use with the learning disabled population because of the language used. It was therefore adapted by simplifying the language and including some visual symbols (appendix H). All the relevant committees approved this adapted form for use.
2.45 Test Administration

The test battery was piloted on three people with learning disabilities who were not included in the final study. This pilot highlighted that the effects of fatigue and loss of concentration needed to be minimised. It was therefore decided that the test battery would be administered over three sessions, each about 45 minutes in length. The tests were administered in the order outlined below in Table 2:

<table>
<thead>
<tr>
<th>Session number</th>
<th>Tests administered</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Picture Memory (CAT), Object Memory (CAT), Card Sorting (CAT), Raven’s Coloured Progressive Matrices</td>
</tr>
<tr>
<td>2</td>
<td>Rivermead Behavioural Memory Test for Children, “Doors A” (DPT), Weigl Color Form Sorting Test</td>
</tr>
<tr>
<td>3</td>
<td>Story Recall (AMIPB), Word-list Learning (AMIPB), Color Trails Test, British Picture Vocabulary Scale-II, Verbal Fluency</td>
</tr>
</tbody>
</table>

Table 2: Order in which tests were administered

Testing was completed at an appropriate location that was convenient for each individual participant. This was either a day centre, workshop or the participant’s home. No participants were excluded or dropped out of the study after the consent stage.
3. Results

3.1 Statistical Analyses

All statistical analyses were completed using the Statistics Package for Social Sciences, version 10.1 (SPSS, 2000). Due to the small size of the sample a conservative approach was taken when selecting appropriate statistical tests for use in this study. A non-parametric test, Mann-Whitney U, was therefore employed to compare the results from the two groups.

3.2 Sample Characteristics

3.21 General Intelligence

General intelligence was measured using the RCPM. Results are given below in table 3:

<table>
<thead>
<tr>
<th>Group</th>
<th>N</th>
<th>Mean score (SD)</th>
<th>Range</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Downs Syndrome</td>
<td>12</td>
<td>16.83 (2.21)</td>
<td>13-20</td>
<td>z (12, 16)= 0.936, p=0.371, 2-tailed test</td>
</tr>
<tr>
<td>Controls</td>
<td>16</td>
<td>16.5 (4.93)</td>
<td>8-27</td>
<td>2-tailed test</td>
</tr>
</tbody>
</table>

There was no significant difference (p=0.371) between the DS group and the control group on this test of general non-verbal intellectual level. Using conversion tables provided in the RCPM test manual, the equivalent mean mental age of the two groups was also calculated (DS group=6.5 years; control group=6.5 years). Mental ages are not normally used in clinical practice, but in this instance can provide a further comparison of the two control and experimental groups. These results suggest that the two groups were matched for non-verbal general intellectual level.

3.22 Verbal Ability

Verbal ability was measured using the BPVS-II. Results are given below in table 4. The DS group performed significantly worse (p=0.000002) on the BPVS-II than the control group. This result suggests that the two groups were not matched for general verbal ability.
Table 4: Descriptive statistics and significance level for the BPVS-II.

<table>
<thead>
<tr>
<th>Group</th>
<th>N</th>
<th>Mean score (SD)</th>
<th>Range</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Downs Syndrome</td>
<td>12</td>
<td>5.49 (1.64)</td>
<td>3.17-7.58</td>
<td>( z (12, 16) = -4.18, p=0.000002, )</td>
</tr>
<tr>
<td>Controls</td>
<td>16</td>
<td>9.88 (2.78)</td>
<td>7.08-16.17</td>
<td>2-tailed test</td>
</tr>
</tbody>
</table>

3.23 Verbal Short-term Memory

*Story Recall (immediate)*

Verbal short-term memory was measured using the AMIPB Story Recall (immediate) sub-test. Results are given below in table 5:

<table>
<thead>
<tr>
<th>Group</th>
<th>N</th>
<th>Mean score (SD)</th>
<th>Range</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Downs Syndrome</td>
<td>12</td>
<td>5.83 (3.56)</td>
<td>2-12</td>
<td>( z (12, 16) = -3.422, p=0.0003, )</td>
</tr>
<tr>
<td>Controls</td>
<td>16</td>
<td>16.00 (9.39)</td>
<td>5-38</td>
<td>2-tailed test</td>
</tr>
</tbody>
</table>

Table 5: Descriptive statistics and significance level for Story Recall (immediate).

The DS group performed significantly worse \((p=0.0003)\) than the control group on this test of verbal short-term memory.

*Word-list Learning*

Verbal short-term memory was also measured by the AMIPB Word-list Learning sub-test. Results are given below in table 6:

<table>
<thead>
<tr>
<th>Group</th>
<th>N</th>
<th>Mean score (SD)</th>
<th>Range</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Downs Syndrome</td>
<td>12</td>
<td>24.75 (5.89)</td>
<td>16-33</td>
<td>( z (12, 16) = -0.328, p=0.767, )</td>
</tr>
<tr>
<td>Controls</td>
<td>16</td>
<td>26.13 (6.97)</td>
<td>18-46</td>
<td>2-tailed test</td>
</tr>
</tbody>
</table>

Table 6: Descriptive statistics and significance level for Word-list Learning.

There was no significant difference \((p=0.767)\) between the DS group and control group on this test of verbal short-term memory. This sub-test involves recalling items on a word-list after each of five presentations. To elicit further information about the performance of the two groups on this task, the number of items recalled after only the first presentation of the list is outlined below in table 7:
There was no significant difference (p=0.945) between the DS group and the control group on the number of items recalled after the first presentation of the word-list.

The number of intrusions (i.e. words said during recall that were not in fact on the word-list) made by each participant on the immediate recall condition of the Word-list Learning sub-test was also recorded. Results are given below in table 8:

<table>
<thead>
<tr>
<th>Group</th>
<th>N</th>
<th>Mean score (SD)</th>
<th>Range</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Downs Syndrome</td>
<td>12</td>
<td>3.92 (3.90)</td>
<td>0-13</td>
<td>z (12, 16) = -0.118, p=0.909, 2-tailed test</td>
</tr>
<tr>
<td>Controls</td>
<td>16</td>
<td>3.63 (2.94)</td>
<td>0-11</td>
<td>2-tailed test</td>
</tr>
</tbody>
</table>

Table 8: Intrusions made on the Word-list Learning immediate recall condition.

There was no significant difference (p=0.909) in the number of intrusions said by the DS group and the control group on the immediate condition of Word-list Learning.

**Corrected Significance Levels**

Using multiple measures of a single construct increases the likelihood of finding a statistically significant result. One way of managing this problem is to use a Bonferroni adjustment to alter the level at which a “p” value is taken to be significant (i.e. the alpha level, which is usually considered to be p=0.05; Breakwell, Hammond & Fife-Schaw, 2000). Both Story Recall (immediate) and Word-list Learning are assessments of verbal short-term memory. It could therefore be argued that such an adjustment should be used. Even when this correction was made, the outcome of the significance tests reported above did not change. The DS group still performed significantly worse (p=0.0003; corrected significance level=0.025) than the control group on Story Recall. There was no significant difference between the DS group and the control group on Word-list Learning (p=0.767; corrected significance level=0.025).
3.24 Visual Short-term Memory

Visual short-term memory was measured by combining the scores from the Picture and Object Memory sub-tests of the CAT. Results are given below in table 9:

<table>
<thead>
<tr>
<th>Group</th>
<th>N</th>
<th>Mean score (SD)</th>
<th>Range</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Downs syndrome</td>
<td>12</td>
<td>11.25 (2.05)</td>
<td>8-14</td>
<td>z (12, 16)=-2.032, p=0.042,</td>
</tr>
<tr>
<td>Controls</td>
<td>16</td>
<td>13.25 (3.70)</td>
<td>6-17</td>
<td>2-tailed test</td>
</tr>
</tbody>
</table>

Table 9: Descriptive statistics and significance level for object and picture memory.

The DS group performed significantly worse (p=0.042) on this test of visual short-term memory than the control group.

3.3 Hypotheses

3.31 Hypothesis 1

Hypothesis 1: “Adults with DS will perform significantly worse on assessments of verbal long-term memory than adults with a learning disability of non-specific aetiology.”

**Story Recall (delayed)**

Verbal long-term memory was measured by performance on the AMIPB Story Recall (delayed) sub-test. Results are given below in table 10:

<table>
<thead>
<tr>
<th>Group</th>
<th>N</th>
<th>Mean score (SD)</th>
<th>Range</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Downs Syndrome</td>
<td>12</td>
<td>3.58 (3.55)</td>
<td>0-10</td>
<td>z (12,16)= -3.473, p=0.0001,</td>
</tr>
<tr>
<td>Controls</td>
<td>16</td>
<td>13.88 (8.15)</td>
<td>4-30</td>
<td>1-tailed test</td>
</tr>
</tbody>
</table>

Table 10: Descriptive statistics and significance level for Story Recall (delayed).

The DS group performed significantly worse (p=0.0001) than the control group on this test of verbal long-term memory. This result supports hypothesis 1.

**Word-list Learning (delayed)**

The delayed recall condition of Word-list Learning (i.e. recall after the distraction list) is also a measure of verbal long-term memory. Results are given below in table 11:
Table 11: Descriptive statistics and significance level for Word-list Learning (delayed).

The DS group performed significantly worse (p=0.0005) than the control group on this test of verbal long-term memory. This result supports hypothesis 1.

Corrected Significance Levels

It could be argued that a Bonferroni adjustment should be employed in this case, as both Story Recall (delayed) and Word-list Learning (delayed) are measures of verbal long-term memory. Even when this correction was made the outcome of the significance tests reported above did not change. The performance of the DS group was significantly worse than the control group on both the Story Recall (p=0.0001; corrected significance level=0.025) and Word-list Learning (p=0.0005; corrected significance level=0.025) sub-tests.

3.32 Hypothesis 2

Hypothesis 2: “There will be no significant difference in performance on assessments of visual long-term memory between adults with DS and adults with a learning disability of non-specific aetiology.”

Visual long-term memory was measured by the Doors A sub-test of the DPT. Results are given below in table 12:

Table 12: Descriptive statistics and significance level for Doors A.

There was no significant difference (p=0.053) between the DS group and the control group on this test of long-term visual memory. This result supports hypothesis 2.
Hypothesis 3: “There will be no significant difference in performance on assessments of everyday memory between adults with DS and adults with a learning disability of non-specific aetiology.”

Everyday memory functioning was measured by the RBMT-C. Six members of the experimental group did not understand the instructions of two sub-tests in this battery (“Picture Recognition” and “Face Recognition”). These were therefore excluded from the analysis. Other results from the RBMT-C are outlined below.

**RBMT-C Delayed Prose Recall**

The RBMT-C Delayed Prose Recall is an everyday assessment of verbal long-term memory. Results are given below in table 13:

<table>
<thead>
<tr>
<th>Group</th>
<th>N</th>
<th>Mean score (SD)</th>
<th>Range</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Downs Syndrome</td>
<td>12</td>
<td>4.29 (3.63)</td>
<td>0-10</td>
<td>z (12, 16)= -2.35, p=0.017, 2-tailed test</td>
</tr>
<tr>
<td>Controls</td>
<td>16</td>
<td>8.72 (5.46)</td>
<td>0-22</td>
<td></td>
</tr>
</tbody>
</table>

Table 13: Descriptive statistics and significance level for RBMT-C Delayed Prose Recall.

The DS group performed significantly worse (p=0.017) than the control group on this test of long-term verbal memory from an everyday memory battery. This result does not support hypothesis 3.

**RBMT-C Delayed Route**

The RBMT-C Delayed Route is an everyday assessment of visual long-term memory. Results are given below in table 14. There was no significant difference (p=0.146) between the performance of the DS group and the control group on this test of long-term visual memory from an everyday memory battery. This result supports hypothesis 3.

<table>
<thead>
<tr>
<th>Group</th>
<th>N</th>
<th>Mean score (SD)</th>
<th>Range</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Downs Syndrome</td>
<td>12</td>
<td>2.5 (1.73)</td>
<td>0-5</td>
<td>z (12, 16)= -1.517, p=0.146, 2-tailed test</td>
</tr>
<tr>
<td>Controls</td>
<td>16</td>
<td>3.44 (1.59)</td>
<td>0-5</td>
<td></td>
</tr>
</tbody>
</table>

Table 14: Descriptive statistics and significance level for RBMT-C Delayed Route.
**RBMT-C Immediate Prose Recall**

The RBMT-C Immediate Prose Recall sub-test is an everyday assessment of verbal short-term memory. Results are given below in table 15:

<table>
<thead>
<tr>
<th>Group</th>
<th>N</th>
<th>Mean score (SD)</th>
<th>Range</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Downs Syndrome</td>
<td>12</td>
<td>6.08 (3.18)</td>
<td>0.5-10</td>
<td>z (12, 16) = -2.255, p = 0.023, 2-tailed test</td>
</tr>
<tr>
<td>Controls</td>
<td>16</td>
<td>8.72 (5.46)</td>
<td>4-23.5</td>
<td></td>
</tr>
</tbody>
</table>

Table 15: Descriptive statistics and significance level for RBMT-C Immediate Prose Recall.

The DS group performed significantly worse (p = 0.023) than the control group on this test of verbal short-term memory from an everyday memory battery. This result does not support hypothesis 3.

**RBMT-C Immediate Route**

The RBMT-C Immediate Route sub-test is an everyday assessment of visual short-term memory. Results are given below in table 16:

<table>
<thead>
<tr>
<th>Group</th>
<th>N</th>
<th>Mean score (SD)</th>
<th>Range</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Downs Syndrome</td>
<td>12</td>
<td>2.67 (1.50)</td>
<td>1-5</td>
<td>z (12, 16) = -1.389, p = 0.189, 2-tailed test</td>
</tr>
<tr>
<td>Controls</td>
<td>16</td>
<td>3.44 (1.55)</td>
<td>1-5</td>
<td></td>
</tr>
</tbody>
</table>

Table 16: Descriptive statistics and significance level for RBMT-C Immediate Route.

There was no significant difference (p = 0.189) between the performance of the DS group and the control group on this test of short-term visual memory from an everyday memory battery. This result supports hypothesis 3.

**Other RBMT-C Sub-tests**

Results of the other RBMT-C sub-tests are given below in table 17. There was no significant difference in the performance of the DS group and the control group on the Name Learning (p = 0.507), Appointment (p = 0.1), Message Immediate (p = 0.664), Message Delayed (p = 0.767) and Orientation (p = 0.059) sub-tests. These results support hypothesis 3.

The DS group performed significantly worse (p = 0.04) than the control group on the “Belonging” sub-test. This result does not support hypothesis 3.
<table>
<thead>
<tr>
<th>Sub-test</th>
<th>Group</th>
<th>N</th>
<th>Mean score (SD)</th>
<th>Range</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name</td>
<td>Downs syndrome</td>
<td>12</td>
<td>1.17 (1.64)</td>
<td>0-4</td>
<td>z (12, 16)= -0.724,</td>
</tr>
<tr>
<td></td>
<td>Control</td>
<td>16</td>
<td>1.63 (1.63)</td>
<td>0-4</td>
<td>p= 0.469, 2-tailed test</td>
</tr>
<tr>
<td>Belonging</td>
<td>Downs syndrome</td>
<td>12</td>
<td>1.75 (1.06)</td>
<td>0-4</td>
<td>z (12,16)= -3.01,</td>
</tr>
<tr>
<td></td>
<td>Control</td>
<td>16</td>
<td>3.25 (1.24)</td>
<td>0-4</td>
<td>p=0.04, 2-tailed test</td>
</tr>
<tr>
<td>Appointment</td>
<td>Downs syndrome</td>
<td>12</td>
<td>0.5 (0.67)</td>
<td>0-2</td>
<td>z (12, 16)= -1.763,</td>
</tr>
<tr>
<td></td>
<td>Control</td>
<td>16</td>
<td>1.06 (0.85)</td>
<td>0-2</td>
<td>p=0.1, 2-tailed test</td>
</tr>
<tr>
<td>Message</td>
<td>Downs syndrome</td>
<td>12</td>
<td>2.42 (0.79)</td>
<td>1-3</td>
<td>z (12, 16)= -0.538,</td>
</tr>
<tr>
<td>(Immediate)</td>
<td>Control</td>
<td>16</td>
<td>2.63 (0.5)</td>
<td>2-3</td>
<td>p=0.664, 2-tailed test</td>
</tr>
<tr>
<td>Message</td>
<td>Downs syndrome</td>
<td>12</td>
<td>2.5 (0.67)</td>
<td>1-3</td>
<td>z (12, 16)= -0.38,</td>
</tr>
<tr>
<td>(Delayed)</td>
<td>Control</td>
<td>16</td>
<td>2.63 (0.5)</td>
<td>2-3</td>
<td>p=0.767, 2-tailed test</td>
</tr>
<tr>
<td>Orientation</td>
<td>Downs syndrome</td>
<td>12</td>
<td>7.92 (1.31)</td>
<td>5-9</td>
<td>z (12, 16)= -1.955,</td>
</tr>
<tr>
<td></td>
<td>Control</td>
<td>16</td>
<td>8.88 (1.15)</td>
<td>6-10</td>
<td>p=0.059, 2-tailed test</td>
</tr>
</tbody>
</table>

Table 17: Descriptive statistics and significance level for other RBMT-C sub-tests.

3.34 Hypothesis 4

Hypothesis 4: “There will be a significant difference in performance on assessments of executive functioning between adults with DS and adults with a learning disability of non-specific aetiology.”

Executive functioning was measured using the card-sorting task from the CAT, the CFST, the CTT and the VFC. Only nine members of the sample could complete the CTT. It was therefore excluded from the analysis. Results of the other executive functioning tests are outlined below.

**CFST**

The CFST was used as a measure of executive functioning. Results are shown in table 18. There was no significant difference (p=0.599) between the performance of the DS group and the control group on this executive functioning test. This result does not support hypothesis 4.
Card-sorting (from the CAT)
This card-sorting test was also used as a measure of executive functioning. Results are given below in table 19:

<table>
<thead>
<tr>
<th>Group</th>
<th>N</th>
<th>Mean score (SD)</th>
<th>Range</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Downs Syndrome</td>
<td>12</td>
<td>100.25 (36.42)</td>
<td>55-170</td>
<td>z (12, 16) = -1.300, p=0.205, 2-tailed test</td>
</tr>
<tr>
<td>Controls</td>
<td>16</td>
<td>83.69 (37.09)</td>
<td>36-154</td>
<td></td>
</tr>
</tbody>
</table>

Table 19: Descriptive statistics and significance level for the card-sorting task.

For this test, the score is the time taken to complete the task. A higher score therefore represents poorer performance. There was no significant difference (p=0.205) between the performance of the DS group and the control group on this executive functioning test. This result does not support hypothesis 4.

VFC
The VFC was also used as a measure of executive functioning. Results are given in table 20:

<table>
<thead>
<tr>
<th>Group</th>
<th>N</th>
<th>Mean score (SD)</th>
<th>Range</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Downs Syndrome</td>
<td>12</td>
<td>9.75 (2.80)</td>
<td>6-16</td>
<td>z (12, 16) = -2.764, p=0.005, 2-tailed test</td>
</tr>
<tr>
<td>Controls</td>
<td>16</td>
<td>14.06 (3.84)</td>
<td>7-21</td>
<td></td>
</tr>
</tbody>
</table>

Table 20: Descriptive statistics and significance level for the VFC.

The DS group performed significantly worse (p=0.005) than the control group on this executive functioning test. This result supports hypothesis 4.

Corrected Significance Levels
The different executive functions are relatively poorly defined (e.g. Wilding, Cornish & Munir, 2002; Pennington, 1997). Some of the tests used in this study may therefore measure the same constructs. As such, it could be argued that a Bonferroni adjustment should be employed to minimise the probability of a Type I error (i.e. reporting a significant effect.
when a real effect is not present). However, even when this correction was made, the outcome of the significance tests reported above did not change. The performance of the DS group was still significantly worse than the control group on the VFC (p=0.005; corrected significance level=0.017). There was no significant difference between the performance of the DS group and the control group on the CFST (p=0.599; corrected significance level=0.017) and the card-sorting task (p=0.205; corrected significance level=0.017).

3.4 Summary of Results

Hypothesis 1
The results supported hypothesis 1. Adults with DS performed significantly worse on assessments of verbal long-term memory than adults with a learning disability of non-specific aetiology.

Hypothesis 2
The results supported hypothesis 2. There was no significant difference between the performance of adults with DS and adults with a learning disability of non-specific aetiology on a test of visual long-term memory.

Hypothesis 3
The results provided mixed support for hypothesis 3. There was no significant difference between the performance of adults with DS and adults with a learning disability of non-specific aetiology on some assessments of everyday memory. However, on other assessments a significant difference did occur.

Hypothesis 4
The results provided mixed support for hypothesis 4. There was a significant difference between the performance of adults with DS and adults with a learning disability of non-specific aetiology on some assessments of executive functioning. However, on other assessments there was no significant difference.
4. Discussion

Before discussing the results relating to the hypotheses of this study some general points need to be made that might have an impact on how the other results are understood. These points concern the sample size and sample characteristics.

4.1 Sample Size

There was a particular difficulty recruiting people with DS to the study and the DS group was therefore smaller than the control group. A number of factors contributed to this problem. Firstly, a relatively high proportion of the DS population have significant hearing and/or visual impairments (for reviews see Davies, 1996; Hammond & Millis, 1996). Participants with these difficulties were not eligible for this study. A second factor, the strict age range criteria for the DS group (18-40 years), also reduced the size of the target population. In addition, some of the day and residential services approached to help with recruitment reported that the majority of their DS service users were over 40 years old. Educational and occupational services might have been more suitable for recruiting younger adults with DS. A third factor was that recruitment occurred through third parties (i.e. day service managers, residential service managers, clinical psychologists). Learning disability services are often very busy environments and recruiting to a psychology study would be a low priority for managers. Therefore, a number of potential participants might not have been approached.

The difficulty recruiting to the DS group meant that the total sample size was less than that needed for a power of 0.7, as outlined in the method section. The probability of a Type II error (i.e. not detecting an effect that is present) was therefore increased. This means the non-significant results of this study need to be interpreted with some caution, particularly those that approach significance.

4.2 Sample Characteristics

4.21 General Characteristics

The DS and control groups had a similar level of general non-verbal intelligence (as measured by the RCPM). However, the DS group performed significantly worse than the control group on the BPVS-II. The BPVS-II is a test of English hearing vocabulary and was
used in the present study to give an indication of the verbal ability of the two groups. This finding therefore needs to be considered when discussing the results of tests with a verbal component.

4.22 Verbal Short-term Memory

The DS group performed significantly worse than the control group on the Story Recall (immediate) sub-test. This is consistent with previous reports of a specific deficit in the verbal short-term memory of people with DS (Jarrold & Baddeley, 1997; Marcell & Armstrong, 1982; Marcell & Weeks, 1988; Wang & Bellugi, 1994). There was no significant difference between the two groups on the Word-list Learning (immediate) sub-test, which is inconsistent with these previous reports. It also contrasts with the study of Vicari, Belluci and Carlesimo (2000), who used a similar list-learning task as a measure of explicit verbal memory. They found a significant effect of group (p<0.001), with DS participants performing worse than controls. This contrast may be due to differences in the words that made up the lists in the two studies. It is difficult to explore this theory further because Vicari and colleagues constructed their own list, which was unreported. The use of a word-list that is part of a standardised test, as in the present research, should facilitate comparison with future studies.

One explanation for the variability in the performance of the DS group across these two verbal short-term memory tests might be differences in the nature of the tasks. Story Recall involves single presentation of the to-be-remembered information, whereas in Word-list Learning (immediate) the list is repeated five times and recall is tested after each repetition. The DS group may therefore have had poorer recall than controls after the first repetition but then “caught-up” with the controls as the test progressed due to ceiling effects (i.e. the control group reached a top limit to what they could recall determined by their level of intellectual disability and the DS group reached this level as the repetition trials progressed). This possibility was explored by an additional analysis that compared recall after the list had been presented just once. However, there was no significant difference in the performance of the two groups at this stage of the task, so this explanation was discounted.

A second difference between the two tasks provides an alternative explanation. In Story Recall (immediate) a lot of verbal information is given in one “chunk” (i.e. the story), albeit contextually organised by the story format. In Word-list Learning (immediate), the verbal
information is given in a number of discrete “chunks” (i.e. the separate words). The discrete presentation may provide enough time for the words in the list to be visualised. The test would then involve both visual and verbal short-term memory, which could benefit the DS group. Future research may be able to test this hypothesis by comparing the performance of people with DS on a list of nonsense words (i.e. phonetic “words” that do not have any meaning) as well as a list of real words.

4.23 Visual Short-term Memory

The DS group performed significantly worse than the control group on a visual short-term memory task. This was unexpected, as previous studies had reported that visual short-term memory in people with DS was comparable to learning disabled controls (e.g. Jarrold & Baddeley, 1997; Marcell & Armstrong, 1982; Marcell & Weeks, 1988; Wang & Bellugi, 1994). This difference between the present results and previous findings might be due to the nature of Picture and Object Memory task used in this study as a measure of visual short-term memory. In these tests, objects and pictures are named when they are presented. As such, the test may be one of verbal as well as visual short-term memory, which would benefit the control group over the DS group.

4.3 Hypothesis 1

The DS group performed significantly worse than the control group on the delayed condition of Story Recall. Although this appears to offer support for the hypothesis that there is a specific deficit in the verbal long-term memory of people with DS, the poorer performance of the DS group on the BPVS-II offers an alternative explanation. It might be the case that the members of the DS group did not have difficulty recalling the story due to a memory impairment. Instead, they might not have been able to understand the story when it was presented due to poorer verbal ability.

Clearer evidence for a specific impairment of verbal long-term memory is provided from the results of the Word-list Learning sub-test. Despite the different verbal abilities of the two groups, they performed similarly on the immediate condition of Word-list Learning (as discussed above). This implies that the words had been encoded into the memory of the two groups to a similar degree. On the delayed condition, however, the DS group performed significantly worse than the controls. The DS participants had therefore either “lost” the
information (a difficulty with memory storage) or could not access it for recall (a difficulty with memory retrieval). These are memory failures and are not related to verbal ability.

4.4 Hypothesis 2

There was no significant difference between the performance of the DS group and the control group on a test of visual long-term memory (Doors A from the DPT). This supports the hypothesis that there is no specific deficit in the ability of people with DS to remember visual information in the longer-term compared to controls. The DS group actually had a better mean score on this task than the control group and the size of this difference approached significance. It may therefore be of interest to repeat this study with a larger sample, especially considering the increased possibility of Type II error in the results of this study (as discussed above).

4.5 Hypothesis 3

Six members of the experimental group could not understand the instructions for two of the RBMT-C sub-tests (Picture Recognition” and “Face Recognition”). These sub-tests were therefore excluded from the study. This might be further evidence of the poorer hearing English vocabulary of the DS group compared to the control group.

The results from the rest of the RBMT-C sub-tests provide mixed support for hypothesis 3. The main focus of this hypothesis was to investigate whether any difficulties with memory in people with DS transferred to everyday situations, as they did not in the one previous study in this area (Numminen, Service, Ahonen & Ruoppila, 2001). In the present study the DS group were significantly worse than the control group on tasks that relied on verbal short-term and long-term memory (Immediate and Delayed Prose Recall). Further, the two groups did not differ significantly on the everyday tasks that relied upon visual short-term and long-term memory (Immediate and Delayed Route). These results support previous findings that people with DS have a deficit in verbal short-term memory but not visual short-term memory and highlight that memory impairments in people with DS do occur in everyday situations. Additionally, these results support hypotheses 1 and 2, in that verbal long-term memory appears impaired but visual long-term memory does not.
The DS group also performed significantly worse than the control group on the “Belonging” sub-test from the RBMT-C. This requires the participant to remind the examiner at the end of testing about a belonging that had been hidden at the beginning of testing. It is therefore a measure of prospective memory. Prospective memory is a store for intentions and plans, rather than a record for past events. It is a good example of a memory function that is often used in everyday life but is little studied by standard memory tests (Cockburn, 1996). On another test of prospective memory from the RBMT-C (“Appointment”), the DS group also performed worse than controls and the size of this difference approached significance. The poorer performance of the DS groups on these tests could be because they did not understand the instructions due to poorer general verbal ability, but could also be indicative of a weakness in prospective memory. It is not possible to draw firm conclusions about this from the present study, but these results suggest further research in this area is warranted.

4.6 Hypothesis 4

Only a few participants could complete the CTT, so it was excluded from the analysis. The CTT was chosen from this study in preference to the TMT because it does not require literacy as well as numeracy skills. However, it does still require the ability to count up to 25, which proved too difficult for the majority of participants.

The results from the other executive functioning tests provided mixed support for hypothesis 4 (i.e. there will be a significant difference in performance on assessments of executive functioning between adults with DS and adults with a learning disability of non-specific aetiology). There was no significant difference between the two groups on either the CFST or the card-sorting test from the CAT. This suggests comparable ability between the two groups in the executive functions these tasks rely upon (i.e. forming abstract concepts, cognitive flexibility, maintaining cognitive set). The DS group performed significantly worse than the control group on the verbal fluency test. This may be indicative of a specific executive functioning deficit in the areas of initiation and interference control, but could also be due to an overall deficit in verbal ability in the DS group. A design fluency task would reduce any influence of verbal skills. Although less well used and researched, such design fluency tasks do exist (e.g. Spreen & Strauss, 1998). It might be possible to adapt these for use in any future study of the executive functioning of people with DS.
Further information about the relative executive functioning skills of the two groups can be obtained by comparing their performance on the Story Recall and Word-list Learning tasks. List learning tasks require the participant to actively organise information. They are therefore more reliant on executive functions than story recall tasks, in which the information is inherently more organised by the story context (Stern & Prohaska, 1996). The better performance of the DS group on the immediate word-list learning task may be explained by comparable ability in some areas of executive functioning between the DS and control groups.

The results of the executive functioning tests are difficult to interpret. Although the DS group was poorer on one test of executive functioning, this test had a large verbal component. As such, this difference may simply represent different levels of verbal ability. The executive functioning of adults with DS therefore needs to be investigated further using a wider range of appropriate tests.

4.7 General Discussion

4.7.1 Interpretation of Differences in Test Performance

The DS group performed significantly worse than the control group on two verbal long-term memory tests (Word-list Learning (delayed) and Story Recall (delayed)). This appeared to be a robust finding, as it also occurred on a verbal long-term memory task from an everyday memory battery (Prose Recall delayed from the RBMT-C). However, the DS group also performed significantly worse on the BPVS-II, a measure of English hearing vocabulary that was used in the present study to give an indication of verbal ability. Therefore, was their poorer memory test performance due to an impairment in verbal memory or did a lower verbal ability mean that they did not encode information into memory at all?

Previous research has suggested that deficits in verbal short-term memory are not due to different verbal abilities (Jarrold & Baddeley, 1997). Furthermore, the results from the two conditions of Word-list Learning in the present study suggest that verbal long-term memory deficits play some role in the poorer performance of the DS group. It is also of clinical relevance that DS participants clearly had greater difficulty recalling verbally presented material than the control group, whatever the cause. This difficulty was apparent in both laboratory style tests and more ecologically valid memory tasks. Therefore, despite some
problems in the interpretation of these results, some implications for our understanding of memory and executive functioning in people with DS and clinical work with this population can be discussed.

4.72 Memory and Executive Functioning in People with DS

The results of the Word-list Learning task suggest that the DS group had a specific deficit in the verbal long-term memory. In contrast, there was no difference between the DS group and controls on a test of long-term visual memory. This supports the idea that memory is not a unitary concept and that different groups can have memory strengths and weaknesses. In addition, differentiating memory in terms of verbal and visual modalities appears to be an appropriate method for highlighting some of these strengths and weaknesses. The variation in long-term memory performance reported here contrasts with the results of Vicari and colleagues (Vicari, Belluci & Carlesimo, 2000). Their DS group performed worse on all the explicit memory tests they employed. However, their memory test battery was considerably smaller than that used in the present study. This highlights the importance of using a range of memory tests to measure different memory functions.

A significant difference between the DS group and the controls was also found on one of the executive functioning tests. Despite this result, more research is needed before hypotheses about specific strengths and weaknesses in this area can be constructed. A useful next step would be to adapt existing batteries that measure executive functioning in people with acquired brain injury (e.g. Behavioural Assessment of Dysexecutive Syndrome; Wilson, Alderman, Burgess, Emslie & Evans, 1996) so that they are useful for people with learning disabilities.

4.72 Clinical Implications

It needs to be emphasised that assessment and intervention with people with DS should occur on an individualised basis. There is a great deal of heterogeneity in the DS population. However, knowledge of relative population strengths and weaknesses can be useful for informing some aspects of this work. What implications for clinical practice are there if the results of the present study generalise?
One implication is in the choice of interventions used to improve the ability of people with DS to remember information. If a practitioner was only aware of a weakness in the verbal short-term memory of people with DS, their choice of intervention may focus on ensuring encoding takes place. This could include repeating information or presenting it in discrete chunks, which might appear to have some benefit (as in the immediate condition of Word-list Learning). However, this study has suggested that people with DS also have difficulty in the retention and/or retrieval of verbal information in the longer-term (as in the delayed condition of Word-list Learning). Ensuring encoding occurs would therefore only have short-term benefits if the information remains primarily in the verbal modality. Strategies used in neuropsychological rehabilitation work that encourage use of visual memory in people who have a relative weakness in verbal memory may be more useful. These include: encouraging individuals to visualise pictures of words and ideas when they are learning new information; providing pictures and written lists of information that is heard and advocating referral to these to enhance recall; and encouraging significant others, such as family members and carers, to use pictures and written lists (Johnstone & Stonnington, 2001). These strategies need to be adapted for people with DS (e.g. more pictorial than written lists) and researched. Those found to be effective could then be emphasised throughout occupational, educational and clinical work with the DS population.

A second implication of the present study relates to wider clinical work with the DS population. The behaviour of people with DS needs to be understood in the context of a relative weakness in verbal memory (both short- and long-term). The teaching of activities of daily living (e.g. travel training) may need to be adapted so that it relies less on verbal memory. As discussed in the introduction, cognitive strengths and weaknesses also need to be considered when formulating challenging behaviour. They might also impact on the development and maintenance of anxiety difficulties (e.g. difficulty with verbal information could lead to high levels of anxiety when going to environments when verbal information is used extensively, such as schools, day centres and work environments. This could result in avoidance). Therapeutic interventions, either individual or group, might also benefit from being adapted to reduce the impact of a verbal memory impairment. This would be particularly relevant for cognitive-behavioural therapy. The results of cognitive testing (e.g. for dementia) need to be interpreted in light of possible pre-morbid weaknesses in verbal memory and executive functioning. It is therefore important that cognitive assessment incorporates both visual and verbal tests, which needs to be considered as test batteries are developed.
A third implication of this study is that it provides additional knowledge about what tests are useful for clinical work with the learning disabled population. The RCPM, BPVS-II, card-sorting test from the CAT and VFC all provided a range of scores and could be employed again in work with people with learning disabilities. These tests may benefit from their relatively simple instructions. Word-list Learning could also be used again, but it might be beneficial to add a recognition component after the delayed condition (e.g. telling the participants the original word-list but with distracters added and requiring them to say whether each word was in the original list). This would provide more information about the stage of memory at which difficulties occur (i.e. storage or retrieval). Doors A could benefit from an increased number of items, which would facilitate the detection of both clinically and statistically significant differences between participants.

Many of the RBMT-C sub-tests have a small range of scores (Name Learning, Appointment, Message Immediate, Message Delayed, Belonging, Immediate Route, Delayed Route). Subtle differences between participants are therefore less likely to be detected. The development of an everyday memory test with increased specificity is needed, particularly for research comparing different groups. The CFST also provides a small range of scores, so has similar limitations. However, it may appropriate for use in detecting change in cognitive functioning within people with learning disabilities in clinical settings. This is the purpose for which it has been employed in the general population (Byrne, Bucks & Cuerden, 1998; Grewal & Hayward, 1984).

Picture Memory and Object Memory offered a range of scores and could be useful in clinical practice. However, they do not appear to be pure measures of visual short-term memory. The Story Recall sub-test of the AMIPB was difficult for the DS group in particular. A similar test with a shorter story would be more useful for this population. The development of a recognition component might also benefit the test (e.g. questions about the story that require a “yes” or “no” response). The CTT was too difficult and was only completed by a minority of the participants. To be useful for the learning disabled population, an alternative measure of cognitive flexibility needs to be developed that does not require either literacy or numeracy skills.
4.73 Critique of the Study

The study had a number of strengths. It used an extensive battery of memory and executive functioning tests, all of which had standardised procedures. This included an ecologically valid memory test that consists of tasks that are analogies of everyday situations. The DS and control groups had similar levels of non-verbal ability and a similar gender mix, thus reducing any influence these variables might have on the results. The age range of the DS group was also limited to 18-40 years in an attempt to minimise any effects from the neuropathology likely to be found in DS adults above this age.

The study also had a number of limitations that need further discussion. As outlined previously, the smaller than expected sample size means that the probability of a Type II error is increased. Caution is therefore needed when interpreting the results of this study, especially non-significant results. This may be particularly relevant for Doors A and the Appointment sub-test of the RBMT-C, which approached significance. As tests with standardised procedures were used, further exploration of these results through replication of the study has been made considerably easier.

The experimental and control groups did not have a similar level of verbal ability as measured by the BPVS-II. This made it difficult to infer what caused some of the between-group differences. It may have been beneficial to match the samples on a case-by-case basis for a range of verbal and non-verbal abilities. This was not possible in the present study due to time constraints and recruitment difficulties.

Only one test of long-term visual memory was used in the present study (Doors A). The choice of this was restricted by the limited number of visual long-term memory tests appropriate for people with learning disabilities. It is also important to note that the time span between the presentation and remembering conditions is not as long in Doors A (approx 1-3 minutes) as in some other long-term memory tests (e.g. the 27-33 minute delay on the Story Recall test) and Doors A is a recognition rather than a recall task. Future research could include comparable recall and recognition conditions across the visual and verbal modalities, as well as similar time spans between presentation and remembering. This would require the development of new tests that are suitable for this population.
As outlined in the introduction, DS is caused by chromosomal abnormalities (for a review see Pennington & Bennetto, 1998). In approximately 95% of cases, this abnormality is an extra copy of chromosome 21 (trisomy 21). In 2-4% of cases the abnormality is that a portion of chromosome 21 becomes attached to another chromosome, typically chromosome 14 (partial trisomy 21). In another 1-4% of cases only a sub-set of an individual's cells are trisomic (mosaic trisomy 21). It is unclear whether these different causes of DS lead to different population characteristics, including cognitive abilities (Pulsifer, 1996). The type of DS was not checked in this study. Given the small proportion of the DS population that is not full trisomy 21, it is unlikely to have had a major impact on the results. However, differences in the chromosomal abnormality causing DS should be excluded as a variable where possible in future studies. A similar problem may have existed with the homogeneity of the control group. Medical records were not checked to identify whether participants had a learning disability of non-specific aetiology, as this raises a number of additional consent and ethical issues. The researcher therefore relied on the knowledge of residential and day service support staff, who may themselves have been unclear about this issue. This means that it is not possible to be certain that the entire control group had a learning disability of non-specific aetiology. If this was not the case, the results may have been biased.

The use of third parties to approach potential participants was done in an attempt to minimise ethical concerns. People with learning disabilities are more likely to acquiesce than members of the general population (e.g. Finlay & Lyons, 2002). It was thought that being contacted initially by someone known (e.g. keyworker, manager) provided a better environment for someone to decline to participate. A problem with this safeguard is that it introduces a possible bias in the people who were being brought to the notice of the researcher for inclusion in the study. It could be that only those people who were considered to be more able, more verbal or likely to say yes were approached. There were no data on the number of people who declined to participate, as only the names of those who agreed were forwarded to the researcher. This could be of particular relevance given the difficulties recruiting to the study. These problems are hard to overcome. One solution might be to identify all members of the learning disabled population in a region (e.g. through a register). They could then be visited with someone they knew well to make an initial enquiry about participation. However, this raises ethical issues about whether this is an appropriate use of such a register. This approach would also be very time-consuming and labour-intensive, and was certainly not possible in the present study given the time constraints.
4.74 Future Studies

Many of the methodological improvements outlined in the above discussion could be combined to improve the design of future studies. This would provide more robust information about the memory and executive functioning of people with DS. An improved memory study would need suitably sized control and experimental groups matched on a case-by-case basis for age, gender, verbal and non-verbal ability. Their performance on visual and verbal memory tests with both short- and long-term conditions would be compared. These tests would have comparable recall and recognition components, similar lengths of delay between conditions and should also include everyday memory tasks. An improved executive functioning study would need similar experimental and control groups to those outlined above. Tests would also need to be at a level appropriate to the groups’ abilities and have a range of scores. It would be beneficial to have verbal and non-verbal tests of each area of executive functioning that is being measured (e.g. both verbal and design fluency). If these improved studies are to occur, tests that are suitable for use with the learning disabled population will need to be developed.

Future research could also build on the present study in an alternative way. The results of functional assessments of memory, such as those reported here, could be compared with studies that have investigated brain morphology in people with DS through Magnetic Resonance Imaging; e.g. Jernigan, Bellugi, Sowell, Doherty & Hesselink, 1993). This could help the development of neuropsychological models of brain-behaviour links (see Lezak, 1995, for an overview). It could also lead to further hypotheses about the cognitive strengths and weaknesses of people with DS based on how well developed the brain structures associated with different cognitive functions are in this population.

In the present study, investigation of the types of memory errors made by the two groups was limited to the number of intrusions made on the delayed condition of Word-list Learning. No significant difference was found in this case. However, further exploration of this area might provide additional information about the memory functioning of people with DS. For example: disorganised approaches to tasks, including memory tasks, may point to executive rather than memory difficulties; a large number of intrusions mixed in with correct answers might suggest that information is being encoded into memory but there are difficulties with accessing that information; and a high level of confabulation may suggest that no information about the task has been encoded in memory or has been “lost”.

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5. Conclusion

The present study has aimed to investigate the strengths and weaknesses in the long-term memory and executive functioning of adults with DS. The performance of a group of adults with DS on standardised tests of long-term memory and executive functioning was compared with the performance of a control group of adults with a learning disability of non-specific aetiology. The results showed that the DS group performed significantly worse than the control group on many of the tests that had a large verbal component, including verbal short and long-term memory tasks and a verbal initiation task. The difficulty of the DS group on verbal memory tasks was also evident in their performance on an everyday memory test.

It was difficult to identify whether some of the differences between the groups were due to impairment in specific cognitive abilities or due to the lower level of general verbal ability in the DS group. However, on one test of verbal long-term memory the DS group did perform significantly worse than the control group despite similar performance on the immediate recall condition of the same test. This suggests that it was the ability to manage verbal information within memory that was the difficulty. Some implications for clinical practice and areas for future research were identified. This included applying some strategies currently used in neuropsychological rehabilitation when working with people with DS and developing further tests suitable for use with the learning-disabled population.
References


AIDS study, cross-sectional phase II: Neuropsychological and neurological findings. *Archives of General Psychiatry*, 51, 51-61.


Appendix A

Approval Letters from Ethics Committees and NHS Trust
Research and Development Steering Group
CERTIFICATE OF LREC APPROVAL

This is to certify that the research proposal entitled

| An Investigation of Long-term Memory and Executive Functioning in Adults with Down's Syndrome |

has passed a process of ethical review by Croydon Local Research Ethics Committee (LREC).

Dr John Chang
Chairman, Croydon LREC

7th October 2002

Please note: Ethical approval does not give you permission to carry out the work within your Trust. This must be confirmed with the Research and Development Department.

What are LRECs?

- LRECs are committees appointed by the Department of Health. The Department of Health requires all research of the kind you have been asked to take part in to be approved by an appropriate LREC.
- LRECs are responsible for assessing whether or not it is ethical for a medical research study to go ahead (according to guidelines issued by the Department of Health, in accordance with basic principles accepted world-wide by the World Medical Association).

What does it mean if research has been approved by an LREC?

If research has been approved by an LREC, this means, among other things, that the LREC is satisfied that

- the researchers are properly qualified;
- a number of legal requirements have been complied with;
- adequate procedures are in place to protect the confidentiality of information;
- the information sheet gives adequate information about what participation in the research involves; about the possible risks and benefits of participation; and about whether or not compensation is automatically available to you if you are harmed as a result of participating;
- adequate procedures are in place for obtaining the free and informed consent of all potential participants.

However

- The fact that research has been approved by an LREC DOES NOT MEAN that the research is safe for you to take part in or that you will come to no harm as a result of doing so. In regard to safety, LREC approval indicates no more than that the LREC is satisfied that the researchers have taken all reasonable steps to minimise avoidable risks.
- All medical research involves risks that cannot be eliminated entirely, and it is up to you to decide whether or not you are willing to undergo the risks involved.
Dear Mr Morris

29JMDS(365) Please use this reference in all correspondence
An Investigation of long-term memory and executive functioning in adults with Down's Syndrome

Thank you for submitting the amendments requested in our letter of 4 November 2002. Your response has now been reviewed by our sub-committee, who were satisfied that it accorded with the committee's decision. I am therefore pleased to confirm that Chair's Action has been taken in approving the above study, on condition that all final agreed documentation is adhered to.

To aid us in monitoring the study, we would be grateful if you could send us an update one year from the commencement of your programmed with the following details:-

1.0 Is the research still continuing?
2.0 If it is, which stage has it reached:-
   2.1 Data being collected
   2.2 Data being analysed
   2.3 Research being written up
   2.4 Research published
3.0 Have there been any serious adverse events?

If you are sending any Protocol Amendments to us, please ensure that you highlight the areas of change.
Dear Mr Morris

An investigation of long-term memory and executive functioning in adults with Down Syndrome (ACE/2002/92/Psych) – FAST TRACK

I am writing to inform you that the University Advisory Committee on Ethics has considered the above protocol under its ‘Fast Track’ procedure and has approved it on the understanding that the Ethical Guidelines for Teaching and Research are observed. For your information, and future reference, these Guidelines can be downloaded from the Committee’s website at http://www.surrey.ac.uk/Surrey/ACE/.

This letter of approval relates only to the study specified in your research protocol (ACE/2002/92/Psych) - Fast Track The Committee should be notified of any changes to the proposal, any adverse reactions and if the study is terminated earlier than expected, with reasons.

Date of approval by the Advisory Committee on Ethics: 20 November 2002
Date of expiry of approval by the Advisory Committee on Ethics: 19 November 2007

Please inform me when the research has been completed.

Yours sincerely

Catherine Ashbee (Mrs)
Secretary, University’s Advisory Committee on Ethics

cc: Chairman, ACE
Dr N Holmes, Supervisor, Dept of Psychology
Dr H Liddiard, Community Learning Disability Service
19th September 2002

Dear Julian

I am writing to let you know that the R&D Steering Group has now agreed your research proposal and will be happy for you to proceed once you have agreement from the East Surrey LREC.

If you let us have a copy of your ethical approval once you receive it and written agreement from the Operational manager of the area where your research will take place we will send you an official research agreement for the project to continue.

Good luck, please do not hesitate to contact this office if you have any queries.

Yours Sincerely,

Terry Joseph

On behalf of Dr Karen Dodd LRDO
Appendix B

Recruitment Letter for Clinical Psychologists
Dear Clinical Psychologist,

I am a Trainee Clinical Psychologist at the University of Surrey. For my final year research project I am investigating long-term memory and executive functioning in adults with Downs Syndrome. This research is being carried out in the Surrey Oaklands NHS Trust region and is supervised by Dr Heather Liddiard (Community Learning Disability Team, 48b Chipstead Valley Rd, Coulsdon, Surrey, CR5 2RA). The study has recently been granted approval by both the Croydon and East Surrey Local Research Ethics Committees, so I now wish to begin collecting data. I am therefore looking for participants who would be willing to take part. To help with this I am writing to a number of clinical psychologists in the region.

I need to recruit 16 adults with Downs Syndrome and 16 adults with a non-specific learning disability, all of who must meet the following inclusion criteria: aged 18-40; significant learning disability (i.e. IQ 55-70 range); verbal communication and English as a first language; no autism or current diagnosed mental health problem; no hearing or sight difficulties.

If you have a client who may be interested in participating, I would be very grateful if you could ask them if they would agree to be approached to discuss the study. If they did agree, could they sign the enclosed form and could you return it to me at the address below? I would then initially meet with him/her to outline the study (I am willing to travel to anywhere in the region). I have information sheets for him/her, parents/carers, keyworkers and advocates. I would also be available to answer any questions that arose. If he/she consents to participate I will administer some tests of long-term memory and executive functioning. These tests have been selected following careful consideration of the population the study is targeting. Testing will take two or three sessions, each lasting one hour.

If you have a client who consents to be approached about the research, or you would like further information about the study, please contact me at the address/e-mail/telephone number below:

c/o Psychology Department (PsychD), University of Surrey, Guildford, Surrey, GU2 7XH

e-mail:  
tel:

Thank you for your help with this study.

Yours faithfully,

Julian Morris  
Trainee Clinical Psychologist
Appendix C

Recruitment Letter for Managers of Residential and Day Services
Dear Manager,

I am currently involved in a research project investigating long-term memory in adults with a learning disability (supervised by Dr Heather Liddiard, Clinical Psychologist, Community Learning Disability Team, 48b Chipstead Valley Rd, Coulsdon, Surrey, CR5 2RA). The study has recently been granted approval by both the Croydon and East Surrey Local Research Ethics Committees and I am now looking for participants who would be willing to take part. To help with this I am writing to a number of learning disability services within the region.

The study involves administering a variety of memory tests to both adults with Down’s syndrome and adults with a learning disability of non-specific aetiology. Those in the Down’s syndrome group need to be aged between 18 and 40 (inclusive). The age range for people in the other group is more flexible. It is anticipated that completion of the memory tests will take 3 sessions, each about 45 minutes in length. I am willing to travel to anywhere in the region that is convenient for the participants and will see people either in the daytime or in the evening. I can meet with you and your service users to discuss the study further and provide an information sheet.

If you know anyone who may be interested in participating in this study, or if you would like further information about it, please contact me at the address/ e-mail/ telephone number below. I will also follow up this letter with a telephone call in the near future. Thank you for your help with this research.

Yours faithfully,

Julian Morris
Trainee Clinical Psychologist

c/o Psychology Department (PsychD), University of Surrey, Guildford, Surrey, GU2 7XH

e-mail: c/o Psychology Department (PsychD), University of Surrey, Guildford, Surrey, GU2 7XH
tel:
Appendix D

Clinical Psychologist/Manager Information Sheet
Clinical Psychologist Information Sheet

Study: An Investigation of Long Term Memory and Executive Functioning in Adults with Down's Syndrome

is being invited to take part in a research study investigating long-term memory and executive functioning in adults with Down's syndrome. The results may help future clinical work with the research population (e.g. in areas of memory assessment and skills teaching). The study will last about ten months but he/she will only be asked to take part for a few days. The researcher will administer a number of psychological tests of memory and executive functioning on different occasions. The testing will not be for more than one hour each time and participants will be encouraged to take a break at any time they would like one. Two groups of people will be tested: an experimental group of adults with Down's syndrome and a control group of adults with a non-specific learning disability.

If__________decides to take part then he/she will receive an information sheet to keep and a copy of the consent form. He/she can withdraw at any time and without giving a reason. This will not affect the standard of care that is received.

All the information given will be stored in a private and secure place. It will be treated confidentially. The only people allowed to see it will be the people involved in the research. It will only be used for the purpose of the research. The responses will be coded with a number so no names will be attached to the name of any individual. All information will be held in accordance with the Data Protection Act (1998).

A report will be written at the end of the research, which describes what was found. There will be no mention of any names, addresses or other personal details anywhere in the final report. This report may be published in a book or journal. This would disseminate the knowledge to other health professionals.

For further information please contact: Julian Morris, Trainee Clinical Psychologist, c/o Psychology Department (PsychD), University of Surrey, Guildford, Surrey, GU2 7XH.

This study has been reviewed by the Croydon Local Research Ethics Committee and the East Surrey Local Research Ethics Committee.
Manager Information Sheet

Study: An Investigation of Long Term Memory and Executive Functioning in Adults with Down’s Syndrome

__________________________ is being invited to take part in a research study investigating long-term memory and executive functioning in adults with Down’s syndrome. The results may help future clinical work with the research population (e.g. in areas of memory assessment and skills teaching). The study will last about ten months but he/she will only be asked to take part for a few days. The researcher will administer a number of psychological tests of memory and executive functioning on different occasions. The testing will not be for more than one hour each time and participants will be encouraged to take a break at any time they would like one. Two groups of people will be tested: an experimental group of adults with Down’s syndrome and a control group of adults with a non-specific learning disability.

If ___________________________ decides to take part then he/she will receive an information sheet to keep and a copy of the consent form. He/she can withdraw at any time and without giving a reason. This will not affect the standard of care that is received.

All the information given will be stored in a private and secure place. It will be treated confidentially. The only people allowed to see it will be the people involved in the research. It will only be used for the purpose of the research. The responses will be coded with a number so no names will be attached to the name of any individual. All information will be held in accordance with the Data Protection Act (1998).

A report will be written at the end of the research, which describes what was found. There will be no mention of any names, addresses or other personal details anywhere in the final report. This report may be published in a book or journal. This would disseminate the knowledge to other health professionals.

For further information please contact: Julian Morris, Trainee Clinical Psychologist, c/o Psychology Department (PsychD), University of Surrey, Guildford, Surrey, GU2 7XH.

This study has been reviewed by the Croydon Local Research Ethics Committee and the East Surrey Local Research Ethics Committee.
Appendix E

Participant Information Sheet
You are being invited to take part in a research study. It is up to you to decide if you want to take part. Before you decide it is important for you to understand why the research is being done and what it will involve. Take as much time as you need to think about participating. Discuss it with your friends, relatives or keyworker if you wish.

If you do decide to take part, you will be given this information sheet to keep as well as a copy of the consent form you will be asked to sign. You are free to stop at any time and nothing will happen.

In this study I want to find out what parts of memory people are good at and what parts of memory people might need help with. This may help change the way some people work (like teachers and psychologists). The study will last about ten months but you will only be asked to take part for a few days.

If you decide to take part I will come and see you at a time and place that is good for you. I will ask you to try and remember different things like pictures, stories and words. I will also ask you to answer some questions and to do some puzzles and things like that. This will not be for more than an hour at a time. When you have finished I will leave you and you will be free to carry on doing what you were doing before.

All the information you gave would be stored in a private and secure place. It would be treated confidentially. The only people allowed to see it would be the people involved in the research. It will only be used for the purpose of the research. The responses will be given a number so no one else will know what you have said.

A report will be written at the end of the research, which describes what was found. There will be no mention of your name, address or other personal details anywhere in the final report. This report may be published in a book or journal. Your name will not be included.

For further information please contact: Julian Morris, Trainee Clinical Psychologist, c/o Psychology Department (PsychD), University of Surrey, Guildford, Surrey, GU2 7XH. Thank you for taking part in this study.

This study has been reviewed by the Croydon Local Research Ethics Committee and the East Surrey Local Research Ethics Committee.
Appendix F

Information Sheets for Advocates, Keyworkers and Parents
Advocate Information Sheet

Study: An Investigation of Long Term Memory and Executive Functioning in Adults with Down’s Syndrome

_____________________________ is being invited to take part in a research study. It is up to him/her whether or not he/she decides to take part. Before he/she decides it is important to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and ask me if there is anything that is not clear or that you would like to know more about.

If _____________________________ does decide to take part then he/she will receive an information sheet to keep and a copy of the consent form. He/she can withdraw at any time and without giving a reason. This will not affect the standard of care that is received.

The aim of this study is to investigate the strengths and weaknesses in the long-term memory of different people. The results may help future clinical work with the research population (e.g. in areas of memory assessment and skills teaching). The study will last about ten months but _____________________________ will only be asked to take part for a few days. If he/she decided to take part I will administer a number of memory tests on different occasions. The testing will not be for more than one hour each time and participants will be encouraged to take a break at any time they would like one. The time and place for the testing can be chosen by _____________________________. Two groups of people will be tested: an experimental group of adults with Down’s syndrome and a control group of adults with a non-specific learning disability.

All the information given would be stored in a secure place. It would be treated confidentially. The only people allowed to see it would be the people involved in the research. It will only be used for the purpose of the research. The responses will be given a number so no one else will know what has been said. All information held is in accordance with the Data Protection Act (1998).

A report will be written at the end of the research, which describes what was found. This will relate to all of the tests completed with every participant. There will be no mention of any names, addresses or other personal details anywhere in the final report. The report may be published in a book or journal. This would disseminate the knowledge to other health professionals.

For further information please contact: Julian Morris, Trainee Clinical Psychologist, c/o Psychology Department (PsychD), University of Surrey, Guildford, Surrey, GU2 7XH.

Thank you for taking part in this study.

This study has been reviewed by the Croydon Local Research Ethics Committee and the East Surrey Local Research Ethics Committee.
**Keyworker Information Sheet**

**Study: An Investigation of Long Term Memory and Executive Functioning in Adults with Down's Syndrome**

[Space for name]

is being invited to take part in a research study. It is up to him/her whether or not he/she decides to take part. Before he/she decides it is important to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and ask me if there is anything that is not clear or that you would like to know more about.

If [space for name] decides to take part then he/she will receive an information sheet to keep and a copy of the consent form. He/she can withdraw at any time and without giving a reason. This will not affect the standard of care that is received.

The aim of this study is to investigate the strengths and weaknesses in the long-term memory of different people. The results may help future clinical work with the research population (e.g. in areas of memory assessment and skills teaching). The study will last about ten months but [space for name] will only be asked to take part for a few days. If he/she decided to take part I will administer a number of memory tests on different occasions. The testing will not be for more than one hour each time and participants will be encouraged to take a break at any time they would like one. The time and place for the testing can be chosen by [space for name]. Two groups of people will be tested: an experimental group of adults with Down's syndrome and a control group of adults with a non-specific learning disability.

All the information given would be stored in a secure place. It would be treated confidentially. The only people allowed to see it would be the people involved in the research. It will only be used for the purpose of the research. The responses will be given a number so no one else will know what has been said. All information held is in accordance with the Data Protection Act (1998).

A report will be written at the end of the research, which describes what was found. This will relate to all of the tests completed with every participant. There will be no mention of any names, addresses or other personal details anywhere in the final report. The report may be published in a book or journal. This would disseminate the knowledge to other health professionals.

For further information please contact: Julian Morris, Trainee Clinical Psychologist, c/o Psychology Department (PsychD), University of Surrey, Guildford, Surrey, GU2 7XH.

Thank you for taking part in this study.

This study has been reviewed by the Croydon Local Research Ethics Committee and the East Surrey Local Research Ethics Committee.
Parent Information Sheet

Study: An Investigation of Long Term Memory and Executive Functioning in Adults with Downs Syndrome

Your son/daughter is being invited to take part in a research study. It is up to him/her whether or not he/she decides to take part. Before he/ she decides it is important to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and ask me if there is anything that is not clear or that you would like to know more about.

If your son/daughter does decide to take part then he/she will receive an information sheet to keep and a copy of the consent form. He/she can withdraw at any time and without giving a reason. This will not affect the standard of care that is received.

The aim of this study is to investigate the strengths and weaknesses in the long term memory of different people. The results may help future clinical work with the research population (e.g. in areas of memory assessment and skills teaching). The study will last about ten months but your son/daughter will only be asked to take part for a few days. If he/ she decided to take part I will administer a number of memory tests on different occasions. The testing will not be for more than one hour each time and participants will be encouraged to take a break at any time they would like one. The time and place for the testing can be chosen by your son/daughter. Two groups of people will be tested: an experimental group of adults with Down’s syndrome and a control group of adults with a non-specific learning disability.

All the information given would be stored in a secure place. It would be treated confidentially. The only people allowed to see it would be the people involved in the research. It will only be used for the purpose of the research. The responses will be given a number so no one else will know what has been said. All information held is in accordance with the Data Protection Act (1998).

A report will be written at the end of the research, which describes what was found. This will relate to all of the tests completed with every participant. There will be no mention of any names, addresses or other personal details anywhere in the final report. The report may be published in a book or journal. This would disseminate the knowledge to other health professionals.

For further information please contact: Julian Morris, Trainee Clinical Psychologist, c/o Psychology Department (PsychD), University of Surrey, Guildford, Surrey, GU2 7XH.

Thank you for taking part in this study.

This study has been reviewed by the Croydon Local Research Ethics Committee and the East Surrey Local Research Ethics Committee.
Appendix G

Local Research Ethics Committee Standard Consent Form
CONSENT FORM

Title of Project:

Name of Researcher:

Please initial box

1. I confirm that I have read and understand the information sheet dated (version ............) for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

3. I understand that sections of any of my medical notes may be looked at by responsible individuals from [company name] or from regulatory authorities where it is relevant to my taking part in research. I give permission for these individuals to have access to my records.

4. I agree to take part in the above study.

Name of Patient  Date  Signature

Name of Person taking consent (if different from researcher)  Date  Signature

Researcher  Date  Signature

1 for patient; 1 for researcher; 1 to be kept with hospital notes
Appendix H

Consent Form for the Present Study
Consent Form

Study: An Investigation of Long Term Memory and Executive Functioning

My name is ____________________________________________.

The researcher has spoken to me about his study. I have agreed to talk to him and take part in the study. I understand that I will be asked to try and remember different things like pictures, stories and words. I will also be asked to answer some questions and to do some puzzles and things like that.

(Please tick box) ..........................................................  

The researcher has explained to me that if I get upset or change my mind and do not want to carry on, then this is OK. If I do not want to take part in the study, my present or future care will not be affected. I can stop at any time I want. If I want I can tell my keyworker that I am upset and would like some support. My keyworker’s name is ________________________.

(Please tick box) ..........................................................

At the end of this study a report will be written describing the information that was found. I know that my name, my address, or any other personal information that I give will not be used.

(Please tick box) ..........................................................

I know that if there is anything I do not understand I can ask and he will explain it.

(Please tick box) ..........................................................

Signed: ___________________________ Date: ________________

Researcher: ___________________________ Date: ________________

CROYDON COUNCIL

Health & Social Services working together for adults with learning disabilities in Croydon