Carers' Experiences of Challenging Behaviours in People with Learning Disabilities: An Interpretative Phenomenological Analysis of Professional Carers’ Understanding of Specific Incidents of Challenging Behaviour

By

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Summary of Academic Dossier

Four essays are contained within this section. They cover four client groups – Adult Mental Health, People with Learning Disabilities, Children and Families and Older People, and are intended to display the depth and variety of work covered over the three years. The essays are presented in the order in which they were completed to show the development of my academic skills during the training.
Cognitive behaviour therapy for anxiety disorders: Discuss with evidence underlying cognitive-behavioural models of PTSD, social phobia and panic disorder, the role of negative interpretations of physical and mental symptoms as maintaining factors.

Adult Mental Health Essay

January 2003

Year One
Panic disorder, social phobia and Post Traumatic Stress Disorder (PTSD) are all forms of anxiety disorder. Various models have been proposed for each of these disorders, and as will be shown in this essay, the models share a common attribute. Specifically, the misinterpretation of physical and mental symptoms is believed to play a key role in the maintenance of each disorder. In the following essay the role of negative interpretations of physical and mental symptoms in the maintenance of panic disorder, social phobia and PTSD will be discussed using evidence underlying cognitive-behavioural models of these disorders. Some of these models are explicitly entitled 'cognitive' rather than 'cognitive-behavioural'. However, they incorporate behavioural components (such as avoidance of certain situations) and thus they are essentially cognitive-behavioural. Therefore for the purpose of this essay, certain 'cognitive' models of anxiety disorders will be considered 'cognitive-behavioural' (this is consistent with other authors e.g. see Musa & Lepine, 2000 p59). For each disorder, a brief definition will first be given. Then, cognitive/cognitive-behavioural models of the disorder will be outlined, specifically focusing on the proposed role of negative interpretations of physical and mental symptoms in the maintenance of the disorder. This will be followed by a discussion of this role, using the relevant evidence. First, panic disorder will be considered, then social phobia, and finally PTSD.

A panic attack can be defined as a sudden feeling of threat, accompanied by a number of physical symptoms such as breathlessness and raised heart beat, and mental symptoms, such as dizziness and feelings of unreality. An individual is classed as having panic disorder if they meet specific Diagnostic and Statistical Manual of Mental Disorders (DSM)-IV criteria (American Psychiatric Association [APA] 1994, cited in Wells, 1997), such as panic attacks that are repeated and unexpected, and followed by at least one month during which the individual is worried about the possibility of another attack (Wells, 1997). Clark's (1986) cognitive model of panic proposes that the crucial factor underlying the occurrence of a panic attack is the individual's tendency to misinterpret somatic sensations as signaling the presence of threat. According to the model, an attack may be triggered by an external cue (such as being in a cinema for an agoraphobic who suffers from panic attacks) or, more frequently, an internal cue (particular bodily sensation). It is argued that the panic
attack sufferer perceives such cues as threatening, resulting in a state of mild anxiety. The bodily sensations that occur during this state (such as raised heartbeat, slight breathlessness) are then misinterpreted as being highly dangerous to the individual—hence they are labeled ‘catastrophic misinterpretations’. Thus perceived threat is heightened, and the individual becomes increasingly anxious, giving rise to an increase in bodily sensations. These sensations are again misinterpreted, and a vicious circle occurs. In this way anxiety escalates, resulting in a ‘panic attack’.

If panic disorder is maintained by negative interpretations of physical and mental symptoms, as Clark suggests, then associations between bodily symptoms and corresponding negative interpretations should be more readily and strongly activated in semantic memory for panic disorder (PD) patients compared to non-clinical control (NC) subjects.

Cloitre, Shear, Cancienne & Zeitlin (1994) aimed to identify whether 24 PD patients would show better explicit and/or implicit memory for word pairs consisting of a bodily sensation and a corresponding negative interpretation compared to 24 NC subjects. Enhanced memory for such word pairs might be expected if associations between concepts for bodily sensations and associated negative interpretations had become strengthened within semantic memory. Twenty-four clinicians with knowledge of CBT for PD were also included, to control for the possibility that familiarity (without fear) would be enough to enhance memory for these word pairs. ‘Threat’ word pairs, as described above, were presented, randomly interspersed with positive (e.g. smiles-elated), neutral (e.g. groceries-coupons), threat-unrelated (e.g. coronary-groceries), positive unrelated (e.g. smiles-chair) and neutral-unrelated (e.g. groceries-lamp) word pairs. For each word pair subjects were asked to indicate how strongly they thought the words in the pair were related on a four-point scale. Exposure time was dependent on how rapidly subjects made this decision—therefore subjects who decided quickly may have been disadvantaged by a brief exposure rate. Following encoding, subjects completed unrelated tasks for nine minutes. Then implicit and explicit memory was tested using a word stem completion task and a cued recall task respectively. PD patients showed better explicit and implicit memory for threat word pairs than positive or neutral word pairs, clinicians showed better explicit
memory for positive word pairs than neutral or threat word pairs, but better implicit memory for threat word pairs, and NC subjects’ explicit memory performance did not differ according to word pair type, but they showed better implicit memory for neutral than positive or threat word pairs. Overall, these findings indicate that PD patients showed better memory for word pairs depicting catastrophic associations than clinicians or NC subjects, consistent with the prediction of enhanced strengthening of the links between concepts representing bodily sensations and negative interpretations within semantic memory in PD patients. In addition, Cloitre et al. (1994) note that the finding of superior implicit memory for catastrophic associations in PD patients provides support for Clark’s (1986 — cited in Cloitre et al. 1994) proposal that catastrophic interpretations of bodily symptoms may occur outside of awareness, thus explaining the ‘out of the blue’ nature of some attacks.

Schniering & Rapee (1997) also investigated the strength of associations between concepts of bodily symptoms and concepts of negative interpretations within semantic memory. They used a lexical decision task. Forty-seven patients with PD diagnosed according to DSM-IV criteria (APA, 1994, cited in Schniering & Rapee, 1997) and 28 NC subjects took part. The basic task involved presentation of the first word of a pair, which acted as a prime, and then the target, and the task was to decide if the target was a word or non-word. It was predicted that if the target word represented a catastrophic interpretation (e.g. coronary) of a bodily sensation prime (e.g. heartbeat), PD patients should be faster to respond than NC subjects, reflecting the stronger association between the two concepts within semantic memory relative to controls. Word pairs were either neutral or threatening, and either related or unrelated. The prime was followed by a non-word on half the trials. Prior to completion of the lexical decision task, subjects were required to first complete a number of self-report measures of anxiety and depression, and second, to hyperventilate for 30 seconds, in order to evoke physical and mental symptoms and catastrophic associations in PD patients. There was no main effect of group and no significant interaction between group, target word type and prime type, showing that PD patients did not respond faster than normal controls when the prime was a bodily sensation and the target was a catastrophic interpretation. Overall, the prediction that associations between concepts of symptoms and concepts of negative interpretations would be stronger in PD
patients than NC subjects was not supported. The authors note that the sample size was large enough to allow for a medium size effect to be identified. Another explanation for the failure to identify the expected finding concerns the hyperventilation exercise. Prior to this exercise subjects were informed that the sensations experienced would be similar to those experienced during panic. For some subjects this might have been quite a revelation, and it is possible that having been alerted to the possible origin of their symptoms, subjects ceased to interpret them catastrophically, and the links between symptoms and interpretations were somehow ‘deactivated’ prior to the lexical decision task.

If negative interpretations of physical and mental symptoms play a role in the maintenance of PD, then treatment aimed at altering these negative interpretations should reduce the frequency of panic attacks. Cognitive-behavioural therapy (CBT) for PD involves challenging the patient’s negative interpretations of their physical and mental symptoms, and replacing them with more rational interpretations. PD patients undergoing CBT might be expected to show a decrease in the frequency of panic greater than that of patients receiving a form of treatment that did not explicitly address negative interpretations, or patients assigned to a waiting list.

Clark, Salkovskis, Hackmann, Middleton, Anastasiades & Gelder (1994) compared the effectiveness of cognitive therapy, applied relaxation and imipramine (a drug prescribed to treat panic disorder) in the treatment of patients with PD. Seventy-two patients who met DSM-III-R (APA, 1987, cited in Clark et al. 1994) criteria for a diagnosis of PD were assigned to one of four groups; cognitive therapy, relaxation, imipramine or waiting list control. Patients assigned to the cognitive therapy or relaxation groups received up to fifteen treatment sessions over 6 months. Patients in the imipramine group receive up to twelve sessions during the first three months, were maintained on maximum dose for the next three months, and underwent a gradual reduction thereafter. Waiting list control subjects received no treatment during the first three months, and were randomly assigned to one of the treatment groups for the next three months. Assessment, by someone blind to group allocation, was conducted at pre-treatment, and again at three months, six months and fifteen months after the study commenced. Only cognitive therapy included cognitive and behavioural
techniques aimed at challenging patients' negative interpretations of physical and mental symptoms, and replacing them with realistic interpretations. During each assessment, patients were required to rate the frequency of anxiety during the previous two weeks, and complete self-report measures detailing body sensations experienced, and interpretations of them. A composite anxiety measure was formed from the information collected during each assessment. At baseline the groups did not differ with regard to this anxiety composite. At three months all treatments were superior to the waiting list as indicated by a reduction in the anxiety composite for those receiving treatment. Comparison between the three treatments revealed that at three months cognitive therapy led to the most significant reduction in anxiety, at six months both imipramine and cognitive therapy were superior to relaxation, and at 15 months cognitive therapy was again the most effective treatment in terms of anxiety reduction. Importantly, a reduction in negative interpretations at six months was predictive of a reduction in anxiety symptoms at 15 months. This finding supports the role of negative interpretations of symptoms in the maintenance of panic disorder. Unfortunately the authors did not distinguish between the different treatments when they correlated negative interpretations at six months with outcome at 15 months. Therefore it is not known whether patients receiving CBT were any more likely to report a reduction in negative interpretations at six months than patients in the other treatment groups.

In summary, the evidence reported here is not totally supportive or the role of negative interpretations of physical and mental symptoms in the maintenance of PD. Nevertheless, there is some evidence in support of this role from studies looking at the strength of associations between related concepts within semantic memory and the effect of reducing negative interpretations of symptoms upon anxiety.

According to DSM-IV (APA, 1994, cited in Rapee & Heimberg, 1997) criteria individuals with social phobia (SP) are fearful of situations where there is a risk that others may scrutinize them. An ongoing fear of situations where there is a potential for embarrassment is a hallmark of SP (Wells, 1997). Implicit in both of these definitions is that people with SP fear negative evaluation by others. Rapee & Heimberg (1997) propose a cognitive-behavioural model of anxiety in SP. It is argued
that upon entering a social situation, the SP person creates a mental image of how they appear to other people in that situation ('the audience'). This image is formed using information from long-term memory, internal bodily cues, and external cues, inferred from the audiences' behaviour. The individual divides their attention between processing the internal image and processing external threat from the environment (e.g. signs of boredom from a person they are talking to). At the same time, the individual predicts the standard that the audience expects from them in that particular situation, and compares this to their mental image of how the audience actually sees them. The individual’s perception of how the audience actually appraise them, based on the mental image, inevitably falls short of the standard predicted to have been set by that audience, and thus negative evaluation by the audience is inferred. The individual then starts to consider the potential negative consequences of such an evaluation. All this has the effect of provoking further anxiety, the cognitive and behavioural components of which further feed-into the individual’s mental image of how they appear to the audience, and the vicious circle is refreshed. In this model, symptoms of anxiety are negatively interpreted in as much as they contribute to the individual’s negative mental representation of how they are being appraised by others. In particular, somatic symptoms of anxiety that are visible to others such as blushing and sweating are likely to further contribute to the individual’s negative evaluation of the mental ‘image’ that they have formed, of how they must appear to others.

As shown above, both Rapee & Heimberg (1997) propose a role for negative interpretation of physical and mental symptoms in the maintenance of SP. Specifically, people with SP are believed to be alert to internal symptoms, continually monitoring them and using them to modify their mental representation of how they appear to the audience. Physical and mental symptoms are subject to negative interpretation in that they contribute to the mental representation that is negatively appraised relative to the hypothesised standard set by the audience. If the negative interpretation of physical and mental symptoms plays an important role in the maintenance of SP as outlined above, people with SP might be expected to be hypervigilant to their bodily sensations in social situations.
Edelmann & Baker (2002) found evidence to suggest that SP subjects overestimated their heart rate during social situations. Eighteen people with SP, 18 people diagnosed as clinically anxious without SP, and 18 NC subjects, were each required to complete four tasks which varied in level of demand, physical effort required, and likelihood of provoking anxiety. Tasks included riding an exercise bike (high demand, high effort), mental imagery incorporating a situation of personal relevance (low demand, low effort, but anxiety provoking for both patient groups), and a nine minute conversation in which subjects had to get to know a stranger (low demand, low effort, but should provoke anxiety in SP subjects). The operational definition of ‘demand’ was not made explicit, so it is not clear why riding an exercise bike should be regarded as generally more ‘demanding’ than getting to know a stranger. Skin conductance, heart rate, and face/neck temperature were recorded for each subject throughout the tasks. In addition subjects completed questionnaires designed to assess anxiety and depression before tasks commenced, and completed self-reports of bodily sensations at regular intervals between tasks. At three points during the conversation task, subjects had to rate sensations. This procedure may have been biased in favour of eliciting more anxiety from the SP subjects, since frequently stopping and starting the conversation may have made it much harder to maintain conversational flow!

Physiological measures did not differentiate between the three subject groups. SP subjects overestimated their heart rate during the conversation task compared to clinically anxious and NC subjects. This finding is consistent with the prediction that SP subjects will be hypervigilant for bodily sensations during social situations.

As mentioned previously, people with SP may be particularly likely to negatively interpret symptoms of anxiety that are visible to other people, such as blushing or sweating. Presumably this is because they are aware that such visible symptoms are noticeable to others, and believe that they will contribute to other’s negative evaluation of them. If this is the case, then it is perhaps surprising that the only physical symptom found to differentiate between SP subjects and the two control groups in the Edelmann & Baker study was not blushing or sweating but heart rate, which is of course not visible to other people. It is possible that the SP subjects used in the Edelmann & Baker study were concerned with symptoms of anxiety in general, as opposed to only visible symptoms, and therefore their self-reports of blushing and
sweating were not significantly different to those of the clinically anxious subjects. To examine more closely the role of negative interpretations of 'visible' symptoms of anxiety it may be useful to focus on studies that have recruited subjects whose social phobia is characterised by their fear of these visible symptoms of anxiety. Mulkens, de Jong, Dobbelaar and Bogels (1999) classified 28 and 29 women into low and high 'fear of blushing' groups respectively, based on their scores on the Blushing, Trembling and Sweating Questionnaire (BTS-Q; Bogels & Reith, cited in Mulkens et al. 1999). The women were exposed to two situations: one designated intensely stressful—sitting with two male confederates to watch a video of themselves singing; the other less stressful but still deemed an unusual situation—sitting with the male confederates to watch a silent 'television test card' (the exact nature of this not reported). Physiological measures of facial temperature and coloration were recorded throughout the two situations, and subjects had to estimate how intensely they were blushing, how fearful they were of blushing, and how anxious they felt, at various intervals throughout the two situations. At the start of the experiment, subjects were entirely unaware of the two situations that they would be exposed to, and this presumably helped to control for the effects of anticipatory anxiety on blushing. Physiological indices did not reveal any significant difference in the intensity of blushing between the high and low fear of blushing subjects and actual blushing intensity was significantly greater for both groups during the high intensity situation. Furthermore, high fear of blushing subjects consistently rated their blushing as more intense than low fear subjects. This is consistent with the notion that people with SP are particularly likely to be aware of their somatic symptoms. Specifically, the finding that symptoms such as raised heart rate and blushing are commonly overestimated in SP is consistent with the notion that these symptoms contribute to the individual's negative appraisal of themselves in the social situation.

The above two studies provide evidence to suggest that people with SP overestimate the intensity of their anxiety symptoms when in social situations. Roth, Antony & Swinson (2001) found that compared to NC subjects, SP subjects were more likely to believe that others would negatively interpret their symptoms. This is an important finding, since it provides support for the role of negative interpretation of symptoms in the maintenance of SP—people with SP negatively interpret their symptoms in as
much as they expect others to evaluate them negatively on the basis of them. Fifty-five subjects who met DSM-IV criteria (APA, 1994, cited in Roth et al. 2001) for SP and 54 NC subjects completed a scale designed to assess interpretations of symptoms. The NC subjects were significantly younger (mean seven years younger) than the SP subjects but there is no apriori reason to suspect that such an age difference would systematically influence the results obtained. Subjects completed two versions of the scale, one where they had to rate how their own anxiety symptoms would be judged by others (‘Actor’ version) and one where they had to rate how they would judge other people’s anxiety symptoms (‘Observer’ version). Each symptom had eight possible interpretations, some extreme (e.g. psychiatric problem) others benign (e.g. normal anxiety). Extreme explanations were also more negative than benign explanations. Evidence indicated that SP subjects were more likely to believe that others would interpret their symptoms in an extreme way, and less likely to believe that they would interpret them in terms of a benign explanation, than NC subjects. However there was also evidence to suggest that SP subjects were likely to judge other’s symptoms in an extreme way, too. Therefore people with SP may interpret others’ visible anxiety symptoms as harshly as they expect others to judge their symptoms. Overall, the findings are consistent with some role for negative interpretation of symptoms in the maintenance of SP.

The findings of the three studies described above are all consistent with the proposal of a role for the negative interpretation of physical and mental symptoms in the maintenance of SP. However what is not clear is the exact mechanism by which this role operates. Perhaps negative interpretations of individual symptoms per se maintain SP, as they appear to in PD. Alternatively, individual symptoms may not themselves be subject to negative interpretation in SP, but awareness of these symptoms may feed into a mental impression of how the SP person thinks they appear to others, which is itself evaluated negatively. Indeed, this seems to be the role most commonly endorsed by theorists such as Rapee & Heimberg, (1997) and Clark & Wells (1995). Another alternative is that regardless of the person’s mental representation, they are aware of their symptoms and believe that others will use the symptoms as information upon which to base a negative interpretation of them. Future research might aim to elucidate these possible alternative contributions to the maintenance of SP.
Certain individuals develop Post Traumatic Stress Disorder, or PTSD, after having experienced a traumatic event. The criteria for diagnosis of PTSD, in DSM-IV (APA, 1994, cited in Foa & Rothbaum, 1998) include experiencing/witnessing death or serious injury (or where these were threatened) and repeated recollections of the event that are intrusive and distressing ('intrusions'). If symptoms persist for over three months, PTSD is defined as chronic. Ehlers & Clark (2000) proposed a cognitive model of PTSD that helps to explain the maintenance of these symptoms. According to the model, PTSD symptoms persist if the individual continues to regard the trauma and resultant factors as representing a sense of current threat. One factor that can contribute to the sense of current threat is the individual's negative interpretation of initial PTSD symptoms. Ehlers & Clark (2000) list four initial PTSD symptoms and possible negative ways in which they might be interpreted. One initial symptom is the reoccurrence of intrusions, or 'flashbacks'. Intrusions involve the individual re-experiencing the event as if it is happening now. This 'here and now' quality is due to the way in which the memory was encoded during the trauma; as a series of sensory impressions rather than an episodic memory embedded in the appropriate temporal context — see Ehlers & Clark (2000). According to the model, if the individual negatively interprets intrusions (for example by thinking that they are going mad) they will try to suppress them. Such a strategy often has the opposite effect; more intrusions occur (Wegner, 1989, cited in Ehlers & Clark, 2000). The persistent re-experiencing of the event in the form of intrusions greatly increases the individual's sense of current threat, thus contributing to the maintenance of the disorder.

The proposed role of negative interpretations of PTSD symptoms in the maintenance of the disorder has received a lot of support from studies investigating interpretations of initial PTSD symptoms. Three studies finding evidence for this proposed role will be described here. First, Clohessy & Ehlers (1999) looked at responses to intrusive memories in 56 ambulance workers. One of their aims was to identify the relationship between negative interpretations of intrusions and PTSD symptoms. Ninety-nine ambulance workers were sent letters inviting them to take part, and questionnaires to complete such as the Post-traumatic Stress Symptom Scale (PSS; Foa, Riggs, Dancu & Rothbaum, 1993, cited in Clohessy & Ehlers, 1999). Fifty-six workers returned the
questionnaires. Given the hypothesised role of intrusive memories and consequent attempts at thought suppression in the maintenance of PTSD, it is possible that those who failed to return the questionnaires did so because they were suffering from PTSD symptoms and wanted to avoid thinking about them. If this were the case then the sample may not reflect the full extent or severity of PTSD symptoms in ambulance workers, but this conjecture would be difficult to validate. As well as reporting their PTSD symptoms, subjects were also required to complete a questionnaire explicitly addressing their endorsement of negative interpretations of intrusions, such as “I will go out of my mind”. Although only twelve participants met DSM-III-R criteria (APA, 1987, cited in Clohessy & Ehlers, 1999) for a diagnosis of PTSD, nearly 50% reported typical PTSD symptoms such as intrusive memories and irritability. Negative interpretations of intrusions were correlated with PTSD severity. In addition negative interpretations of intrusions were correlated with the degree of distress caused by the intrusions, and negatively correlated with the perceived control over the intrusions. An important finding was that only negative interpretations of intrusions, not positive interpretations, were related to PTSD severity, implying a specific role for negative interpretations in the maintenance of the disorder. Despite the authors’ implication of a causal relationship between negative interpretations of intrusions and PTSD severity in this study, the cross-sectional nature of the research did not allow for such conclusions.

Second, Steil & Ehlers (2000) conducted two studies on survivors of road traffic accidents (RTAs). One aim was to establish whether negative interpretations of intrusions would be substantially correlated with PTSD symptom severity. In the first study 159 RTA victims responded to newspaper reports and radio interviews describing the project. They were then contacted by telephone and given a further explanation of the project, and those who agreed to take part were sent questionnaires. There was a high return rate (84%), and the majority of subjects were women. In study two 138 RTA victims responded to a newspaper report. All who responded were sent questionnaires and the return rate was 66%. The majority of subjects in study two were men and the accidents were more severe than those reported by study one subjects. Factors assessed included accident severity, frequency of intrusions, PTSD symptoms and negative interpretations of intrusions. Questionnaires sent out in
study two enabled a broader range of negative interpretations of intrusions to be measured, and also included a measure of catastrophic interpretations of typical anxiety symptoms. Approximately half of the participants in each study met DSM-III-R criteria for PTSD, and intrusions were among the most common symptoms. Negative interpretations of intrusions were highly correlated with PTSD severity. Negative interpretations accounted for 20% of the variance in PTSD symptom frequency in study one, and 37% in study two. In study two, even when the effect of catastrophic interpretations of typical anxiety symptoms was partialled out of the analysis, negative interpretations of intrusions still accounted for a significant proportion of the variance in ‘unhelpful’ coping strategies such as rumination, that serve to maintain PTSD. This finding provides support for an independent role for negative interpretation of specific PTSD symptoms (not just typical anxiety symptoms) in the maintenance of PTSD. In addition, frequency of intrusions alone was only weakly associated with PTSD severity, implying that negative interpretations of intrusions play a crucial role in the maintenance of the disorder (Steil & Ehlers, 2000).

Third, Dunmore, Clark & Ehlers (2001) used a prospective design to investigate the role of cognitive factors in PTSD that persisted following physical or sexual assault. The advantage of such a design in that it is possible to identify whether negative interpretations of intrusions actually do play a causal role in the maintenance of the disorder, as Ehlers & Clark (2000) maintain. Fifty-seven subjects, all of whom were assaulted in the previous four months, took part. Only six participants had experienced sexual assault, the rest had experienced physical assault. The subjects were given a semi-structured interview initially, during which they were required to complete questionnaires detailing cognitions during and post-assault, negative interpretations of initial PTSD symptoms (including intrusions) and dysfunctional control strategies such as avoidance and though suppression. They were then posted questionnaires every month for nine months after the assault, assessing symptoms of PTSD and depression. The attrition rate was relatively low; 79% of those who initially took part completed the nine-month assessment. Importantly, negative interpretations of initial PTSD symptoms at interview were significantly related to PTSD severity at both six and nine months, even after controlling for severity of the
assault, and initial PTSD severity. The results of this study provide support for a causal role of negative interpretations of PTSD symptoms in the maintenance of the disorder.

Taken together, the results of the three studies described above appear to provide compelling evidence for the role of negative interpretations of initial PTSD symptoms in the maintenance of the disorder.

In conclusion, the degree of support for the role of negative interpretations of physical and mental symptoms in the maintenance of anxiety disorders appears to vary according to the disorder. In the case of PD, the evidence is mixed. Studies examining the strength of the association between concepts representing physical/mental symptoms of anxiety and those representing negative interpretations are promising in that they provide a direct test of these hypothesised associations. Therefore problems inherent in the use of retrospective self-reports, such as mood effects and context effects (see Dalgleish & Watts, 1990, cited in Westling & Ost, 1993) are avoided. However studies utilising this paradigm have not found much support for the hypothesised associations. In the case of SP, negative interpretations of physical and mental symptoms do appear to play some role in the maintenance of the disorder. However the level at which negative interpretations are directed—whether at individual symptoms of anxiety themselves, or at the person’s mental representation of how they appear to others, to which symptoms have contributed—is not clear. The most compelling evidence for the role of negative interpretation of symptoms in the maintenance of an anxiety disorder appears to be in the case of PTSD. Numerous well-designed studies have been conducted specifically to investigate the proposed role of negative interpretations of initial PTSD symptoms in the maintenance of the disorder. In particular, studies appear to be characterised by large sample sizes, ensuring adequate statistical power to detect hypothesised relationships.
REFERENCES


Describe and discuss some of the issues involved in assessing consent in people with learning disabilities

People with Learning Disabilities Essay
July 2003
Year One
Introduction
Several cases have been highlighted in the literature, drawing attention to the issue of assessing consent in people with learning disabilities (LD). For example the authors of a research study looking at causes of pica behaviour in people with LD assumed that none of the potential participants were capable of giving informed consent to invasive procedures such as blood tests on the basis of staffs’ opinions alone (Iacono & Murray, 2003). In the case of L versus Bournewood Community Trust, the House of Lords ruled that a 48 year old autistic man who could not speak was lawfully detained in hospital despite apparently receiving no assessment of capacity to consent (Diesfield, 2000). Hart (1999) identified several cases of people with LD who had been refused the chance to sign their own consent form for hospital treatment in favour of a relative doing it, despite the fact that consent by proxy is unlawful under British law. Hart (2001) reported the case of “Jim” a man with LD who suffered pain needlessly because he was deemed unable to consent to dental treatment and his dentist did not wish to take responsibility for treating him.

Such cases have sparked interest (and in some cases review) of the standards used to assess consent in those with “mental impairment”. Questions have been raised about whether current standards are a fair reflection of the way that non-learning disabled people make decisions, and numerous factors that could influence whether a person is deemed capable of consenting have been identified.

In the following essay some of the issues involved in assessing consent in people with LD will be described and discussed. First, current criteria for assessing consent will be presented and the concept of ‘best interests’ will be considered. Then the issue of normative versus descriptive models of decision making and their relationship to current standards will be discussed. Several other issues involved in assessing consent will then be described and discussed, and throughout the essay an attempt will be made to relate the issues to current standards for assessing consent. Finally the author will conclude that it is important to achieve a balance between setting standards that are rigorous enough to allow the individual with LD to be protected from harm but that continue to reflect the way that non-learning disabled people make decisions.
Standards

According to the Draft Mental Incapacity Bill (British Government, June 2003) a person is deemed to lack capacity with regard to a particular context if at that time they cannot make a decision regarding the matter because of a disturbance of mind/brain functioning. The person is deemed unable to decide for himself or herself if they fail to meet any of the following criteria:

1. Ability to understand decision-relevant information;
2. Ability to retain that information;
3. Ability to use that information in the process of making a decision;
4. Ability to communicate the decision.

Implicit in the above are certain assumptions. One is that a functional approach should be adopted when assessing capacity. This approach assumes that capacity should be assessed in relation to the specific decision-making context in hand. It can be distinguished from the diagnostic approach, which assumes that an individual lacks capacity across situations simply because of their diagnosis, and the outcome approach, which assumes that an individual lacks capacity if their decision goes against the advice of the majority (see Murphy and Clare 2003 for a discussion of these alternative approaches). Another assumption is that the person will make a reasoned decision based on the information that they have been provided with (see criterion 3. above). This implicit assumption becomes more ‘weighty’ given that the information provided should include consequences of any decision made (see p. 2 of the Draft Bill). A third assumption is that in deciding ‘for themselves’ the person’s decision must be made voluntarily, free from coercion. A number of authors have explicitly listed the idea of voluntariness as a criterion to be considered when assessing consent (see Rosenfeld, 1998; Arscott, Dagnan & Kroese, 1998).

The concept of ‘best interests’ would be pertinent to address in outlining current standards. This refers to the idea that if a person lacks capacity then any decision made on their behalf must be in their best interests. The Government’s Draft Incapacity Bill suggests that the views of carers should be elicited if “practicable and appropriate” (see p 2 item 4) but who decides if and when such a procedure would be
appropriate? Gunn (1994) expressed concern about the possibility that ‘best interest’ decisions run the risk of being made in a closed shop, whereby the professional supporting the decision consults with other like-minded professionals and the views of family/carers don’t receive consideration. One could speculate that a similar situation occurred in the L versus Bournewood case, where it would appear that the psychiatrist who initially admitted Mr L failed to consult with a clinical psychologist who may well have been of the opinion that Mr L would have been better off remaining at home where the communicative functions of his self-injurious behaviour could have been analysed.

Do the standards reflect the way decisions are made by non-learning disabled people?

Harris (2003) proposes that the standards currently held for assessing capacity to consent in people with LD reflect an idealised ‘normative’ model of decision-making. Such a model assumes that the individual, through a lengthy process of deliberation, combines the utilities of certain outcomes with the likely probabilities of achieving those outcomes in order to arrive at the ‘optimal’ decision. Harris points out that this model does not allow for the influence of past experiences of the individual and the values held by society. A ‘descriptive’ model, in contrast, allows for such influences and does not assume the optimal decisions will always be made under idealised conditions. Harris argues that the prevailing concept of capacity assumes that choice is determined by individual psychological abilities such as ability to understand the relevant information and ability to weigh up relative costs and benefits. He also argues that according to current standards the influence of society is seen as a potential source of bias and is thus discouraged. Harris proposes that such standards do not reflect the way that day-to-day decisions are made by people without LD. There is evidence to support this for example research on people without LD has revealed the common application of heuristics or ‘rules of thumb’ to simplify decision making (Tversky & Kahneman, 1974, cited in Dye, Hare & Hendy, 2003), although this can lead to biased decisions.

Other authors have highlighted the risks of setting unrealistically high standards for people with LD in relation to specific contexts. For example with respect to sexual
relationships, Murphy & Clare (2003) point out the possibility that staff in residential settings may decide upon the appropriateness of sexual relationships based on criteria such as the amount of time the couple spend together during the day. They question whether staff apply such criteria equally to their own relationships? Sundram & Stavis (1994), cited in Kennedy & Niederbuhl, (2001) note that in some American states in order to be deemed capable to consent to a sexual relationship, the person must “recognise societies views with regard to certain sexual behaviours”. Kennedy & Niederbuhl propose that members of the general public may well not apply this standard so should we expect people with LD to apply it?

Generalised assessments of capacity
Generalised assessments of capacity usually consist of a number of hypothetical vignettes relating to consent to hospital treatment for example. The person is presented with the required information regarding the proposed treatment, likely consequences, alternatives etc, and is then asked a number of questions to assess their capacity to consent. Such procedures run the risk of being in keeping with the diagnostic approach rather than the functional approach because of the hypothetical nature of the material presented. Nevertheless they are still employed. One potential problem with such tests is that the use of hypothetical vignettes may not validly reflect the way the person would behave if actually in that situation. The validity of such assessments is thus rather dependent on the ability of the person to imagine themselves in the situation depicted — this could be quite demanding for many without learning disabilities, and thus possibly very effortful for someone with a learning disability. To illustrate, consider the case of the woman cited in Berghmans (2001) who, although able to consent to having a gangrenous leg amputated when the situation was posed hypothetically, was totally unable to contemplate amputation of her own gangrenous leg (because she denied that it was gangrenous). Given this example it is plausible that someone might appear to be capable of consenting on the basis of their performance on a standardised assessment, but be incapable when in the actual situation because they cannot appreciate the personal significance of what is happening.
Another criticism of standardised assessments is that performance is to some extent determined by a person's prior experience of the situations depicted in the vignettes. For example Morris, Niederbuhl & Marr (1993) used hypothetical vignettes to assess capacity of people with mild-moderate LD to give informed consent. They found that those with LD were able to demonstrate increased knowledge following the vignette about a proposed behavioural treatment, as compared to the vignettes regarding surgery or medication, and they proposed that this may be because of participant's prior experience of behavioural interventions. This raises the possibility that a person may be presumed to lack capacity to consent as a result of their performance on a standardised assessment because they lack familiarity with the situation depicted in whichever vignette is employed. However they may in fact be able to demonstrate capacity when in the actual context in which consent is required because of familiarity (Murphy & Clare, 2003). Of course this latter problem is avoided if a purely functional approach is adopted since capacity to consent is assessed within the specific decision-making context in question.

Morris et al. (1993) noted how variations in the behaviour of those administering the assessments in their study could have affected the categorisation of participants as capable or incapable. They found that if one criterion (e.g. demonstration of knowledge regarding the proposed treatment), was clearly satisfied, then assessors sometimes allowed this to substitute for another criterion that was not so well demonstrated, (e.g. consideration of costs and benefits of the treatment). The authors also noted variations amongst assessors in the degree of teaching of information rather than mere disclosure. Such variations amongst assessors could clearly influence the outcome for those being assessed.

**Presentation of Information**

Leading on from the point made above about teaching versus disclosure of information, presentation of information relevant to the decision is of the upmost importance when assessing consent in someone with LD. It is particularly important because one of the criteria listed by the Government in their Draft Incapacity Bill as suggesting lack of capacity is failure to understand information relevant to the decision, and satisfaction of the remaining criteria is arguably dependent upon the
The ability of a person with LD to understand the information presented to them will depend upon an interaction between the way in which the information is presented and the particular pattern of strengths and weaknesses in sensory and cognitive functioning demonstrated by that individual. For example someone with poor verbal language skills may have their understanding enhanced by presenting the information pictorially. Similarly, someone with memory difficulties may benefit from having information presented to them in ‘chunks’ to lessen the load on memory (Murphy & Clare, 1997). Arscott *et al.* (1998) suggest assessing memory and cognitive deficits prior to assessing capacity, so that information can be presented in a way that maximises a person’s potential for understanding. However depending on how formal and extensive these assessments are, one runs the risk of creating another situation for which consent must be assessed, in addition to the original one! Iacono & Murray (2003) note that in attempting to gain informed consent from people with LD to take part in research studies, it is up to the researcher to *write* information at a level appropriate for the potential participants. In using the word ‘write’ they seem to be taking an unnecessarily restrictive view of the process of conveying information. Green (2001) gives a good account of how information was presented in a way that maximised the opportunity for a young woman with LD to pursue an allegation of sexual assault. Ms S alleged that her former male carer had assaulted her, and the police referred Ms S to a clinical psychologist to assess whether she was able to consent to a sexual relationship. The psychologist took account of Ms S’s fondness for television and showed her a video on sex education and photos relating to rejecting sex. These materials sparked a discussion about consent to sex, and the psychologist was able to conclude that Ms S did have the capacity to consent, but appeared not to have consented. Had she been less inventive in her assessment (for example by just presenting information verbally) the psychologist might have erroneously concluded that Ms S lacked the capacity to consent.
Voluntariness of decisions

As noted in the previous discussion of standards to be adopted when assessing consent, an implicit assumption within the Government’s criteria appears to be that the person’s decision is voluntary. However, a number of factors can influence the degree by which the decision of a person with LD can be considered ‘voluntary’.

People with LD appear to have difficulty understanding their legal rights, for example the right to refuse to consent to treatment or participation in research, or to withdraw their consent (Morris et al. 1993; Wong, Clare, Holland, Watson & Gunn, 2000, cited in Murphy & Clare, 2003). The implication of this is that some people with LD may give their consent not because they want to but because they do not think they have a choice, thus calling into question the voluntariness of their decision. Morris et al. suggest that this lack of awareness of their rights originates from people with LD having prior experience of lack of choice in their lives. Schloss, Alper & Jayne, (1993) cited in Iacono & Murray, (2003) proposed that people with LD have few opportunities to decide for themselves, thus their decision making skills are poorly developed, and a vicious circle occurs whereby further opportunities for decision making are lost. Related to this, Hillary, Tomkin, McAuley, Keane & Staines (1998) suggest that people with LD should have training in decision-making built into their life plans. Such training and increased opportunities for decision making should serve to increase the awareness of people with LD regarding their right to choose, thus hopefully increasing the voluntariness of their decisions.

A pertinent issue to consider here is that the person with LD may perceive an imbalance of power between themselves and others present during the decision making process. Dresser (1999) cited in Iacono & Murray (2003) urged caution in engaging a family member, paid carer or professional in ‘helping’ a person with LD to make a decision. Dresser noted that the person with LD may perceive all of these people as being in a position of power, and this may potentially affecting the degree of voluntariness of their decisions. Related to this is the concept of acquiescence. Acquiescence can be defined as agreeing to a question or statement no matter what its content (Block, 1965, cited in Finlay & Lyons, 2002). Several authors have noted an increased tendency to acquiesce amongst people with LD (e.g. Clare & Gudjonsson,
1995, Henry & Gudjonsson, 1999, both cited in Finlay & Lyons, 2002). Finlay & Lyons note that acquiescence is more likely to occur when the person is uncertain of the answer to the question. According to Gudjonsson (1990) cited in Finlay & Lyons, (2002), acquiescence functions to maintain self-esteem, since it makes a person appear more certain than they actually are. It is also possible that acquiescence is demonstrated in an attempt to please the person asking the questions, since the person with LD may perceive them to be in a position of power.

Types of question used in order to assess capacity to consent
As the standards set out at the beginning of this paper show, in order to be deemed capable of consenting the person with LD must demonstrate his/her ability to understand decision relevant information, retain that information, and use that information in the process of making a decision. How well the person demonstrates these abilities may be highly influenced by the type of questions that the assessor uses to elicit the information. There seems to be a consensus emerging in the literature, pointing to the use of open-ended questions to allow the person with LD to best demonstrate their understanding of decision-relevant information (e.g. Rosenfeld, 1998; Dent, 1986, cited in Bull, 1995; Roth et al. 1982, cited in Murphy & Clare, 2003). Rosenfeld (1998) suggests that if the person is unable to demonstrate their understanding in their own words, then a mixture of yes/no and true/false questions should be used. Sigelman, Budd, Spanhel & Sehoenrock (1981) cited in Bull (1995) note that people with LD may be more prone to “yea-saying” (saying “yes”) in response to yes/no questions. According to Finlay & Lyons, (2002), acquiescence can be detected using oppositely worded yes/no questions e.g. “are you happy” / “are you sad?” Answering yes to both questions would be inconsistent and may suggest acquiescence. Sigelman et al. found that verbal either/or questions, e.g. “are you usually happy or sad?” elicited more consistent responses than yes/no questions, but pictorial either/or questions elicited more answers and more consistent answers than verbal either/or questions. The assumption with oppositely worded yes/no questions is that a “yes” in response to both questions is illogical and indicates acquiescence. However Finlay & Lyons (2002) point out that this needn’t be the case. They give the example of “are you treated fairly” / “are you treated unfairly?” A “yes” in response to both questions isn’t necessarily illogical. Rather, the person may be drawing on
different experiences when answering each question. The authors note that if the technique of asking questions opposed in meaning is to be used to check for acquiescence, then questions must be constructed so that a “yes” answer to both really is logically inconsistent. The research above suggests that a variation of questions may be needed if one is to maximise the chance that a person with a LD will demonstrate their abilities with respect to the decision in-hand, and to control for the possibility of invalid responses due to acquiescence. A potential problem is that repeated questioning on the same topic may inadvertently lead the person with LD to change their answer, assuming that it must have been wrong in the first place (Bull, 1995). Finlay & Lyons (2002) suggest that this can be avoided by explaining at the outset that repeated questions do not mean that the person’s initial answer was wrong. Given that one cause of acquiescence is believed to be uncertainty, Finlay & Lyons (2002) suggest including ‘don’t know’ as a possible answer. The difficulty with including another possible option in a forced-choice format is that the question becomes more like a multiple choice format and there may then be problems with regard to the person’s ability to retain all the information. However Dye et al. (2003) note that such problems have been overcome through the use of pictorial multiple choice questions.

It was previously noted that the ability of a person with LD to understand the information presented to them will depend upon the interplay between how the information is presented, and that persons individual profile of strengths and weaknesses in terms of their sensory and cognitive functioning. From the literature reviewed in the section above, it is evident that the person’s ability to demonstrate their capacity to consent is also dependent upon the interaction between their cognitive/sensory profile and the way in which questions are framed and presented in order to assess that capacity.

**Expression of choice**

According to the Government’s Draft Incapacity Bill, ability to communicate a decision is the last criterion that must be fulfilled in order for a person to be deemed capable of giving or refusing consent. This last stage is very important; a person with LD could, hypothetically, have the capacity to fulfil all the criteria listed in the
'standards' section above, but perhaps be unable to express their understanding or their choice verbally. One could conceive of a situation whereby because of lack of awareness /sensitivity /imagination on the part of those assessing consent, the person is not given the opportunity to express themselves in any other way, and poor expressive language ability is interpreted as indicative of lack of capacity. Such a sorry state of affairs need never arise provided enough effort is devoted to allowing the person with LD to express themselves, for example by presenting information and questions using a variety of formats. Wong, Clare, Gunn & Holland (1999) suggest that where a person's expressive communication ability is poor, augmentative and alternative communication devices may facilitate communication. However the authors note that the validity of responses elicited using such devices may be questionable, if the person has not had sufficient experience of using the device outside of the decision-making context. Such a situation may arise if the device were given to the person with LD with the specific intention of assessing their capacity to consent in a particular situation.

Harris (2003) suggests that carers should use 'dramatic communication' to highlight different options for the person with LD, in order to facilitate choice making. What exactly is meant by 'dramatic communication' is unclear, however there may be a risk of promoting increased opportunities for carers to exert an influence over the choices made! Presumably 'dramatic communication' would involve some sort of non-verbal gesturing, which leads to the next point. Guess, Benson & Siegel-Causey (1985) cited in Harris (2003) note the need for carers to be sensitive to non-verbal communication (NVC) especially in the case of people with LD who have verbal communication problems. But what about cases where the person has verbal communication but their NVC appears inconsistent? Should one interpret NVC preferentially over verbal communication? Hart (1999) did exactly that. She invited people with LD to participate in a research study to examine the experiences of people with LD who received treatment in general hospitals. She notes that one person verbally expressed his willingness to take part in the study, but was excluded because he 'looked tense and anxious'. Was Hart's decision to overrule his verbal consent the correct one? One can think of a number of situations where non-learning disabled people might demonstrate inconsistent verbal and non-verbal communication, but it is not usual
practice to go against their verbal communication on the basis of their non-verbal communication. Take the example of someone who completes a parachute jump for charity. They may be looking forward to this once in a lifetime experience for a number of weeks before the event. They may also appear rather anxious immediately prior to jumping, but would this be an adequate enough reason to prevent them from jumping, especially given their verbal protestations that they wish to go ahead? This last point relates back to the issue considered earlier, i.e. whether people with LD should be expected to meet different standards to those met ordinarily by the non-learning disabled members of our society.

Finally with regard to expression of choice, it is important to consider the part that the persons pre-existing values and beliefs play in his or her decision. Berghmans (2001) suggests that in assessing capacity there is a tendency to concentrate too much on the person's cognitive abilities and not enough on the meaning that the decision holds for that particular patient. Other authors propose that if a person is capable of consenting, their decision should reflect their pre-existing values and beliefs (e.g. Rosenfeld, 1998; Appelbaum & Grisso, 1988, cited in Bridgman & Wilson, 2000). An outcome approach to assessing consent would suggest that capacity should be questioned when the person makes a decision that seems irrational and risky and appears to go against their best interests. However a number of cases have come to light (not necessarily involving people with LD) whereby such decisions have been allowed to stand because they have been shown to be consistent with the persons pre-existing values and beliefs. The case often cited in the literature is that of the Jehovah's witness who's decision to refuse a blood transfusion despite risk of death was honoured given her pre-existing religious beliefs. Another case is that of the man who refused to have his gangrenous leg amputated and later died as a result. His decision was honoured because of his pre-existing belief that he would not go to heaven unless his body was 'whole'.

**Conclusion**

The author has attempted to describe and discuss a number of issues involved in assessing consent in people with LD. An attempt has been made to demonstrate the interplay between the issues themselves, and to show how they relate to current
standards for assessing consent proposed by the British Government. It is evident that a balance needs to be achieved between on the one hand preserving the individual’s right to the same level of autonomy as that enjoyed by the non-learning disabled population, whilst on the other hand recognising that people with LD are vulnerable and that therefore adequate measures must be taken to prevent them from harm.

Harris (2003) implies that the standards that the government currently demands in order for a person to be deemed ‘capable’ are too normative and do not adequately reflect the way that decisions are made in reality, neither do they acknowledge the value of societal influence in facilitating decision making. As shown in this essay, Harris is arguably correct in his assertion that decision making does not ordinarily take place under “optimal” conditions, and it is likely that the person with LD will be subject to a wide range of outside influences when attempting to come to a decision. However Harris seems to assume that the majority of external influences that bear upon a person’s decision making are constructive and thus should be encouraged. As has been demonstrated in this essay, this may not always be the case. The danger of such an assumption is that it is then possible to overlook the fact that people with LD are a vulnerable group and therefore certain safeguards must be in place to ensure that they are protected. In the author’s opinion the Governments standards, in their current form, are necessary to ensure that society does not lose sight of this fact.
References


What developmental and psychological theories could explain Asperger's Syndrome and what implications do these have for assessment and intervention?
Introduction

Asperger (1944, cited in Bowler, 1992) first described children with normal speech development but impaired non-verbal communication (NVC) and social skills. Asperger first labelled these children as having "autistic psychopathy". Since then, the label "Asperger’s Syndrome" (AS) has been adopted, and is used to describe children and adults with normal language development and average/above average IQ who show a primary deficit in reciprocal interaction (Wing, 1981), pedantic speech, unusual and obsessive interests, repetitive actions, impaired NVC and motor ill-coordination. At about the same time as Asperger, Kanner (1943, cited in Frith, 1991) also published work detailing cases of children with unusual behaviours, but these childrens’ language development was significantly delayed. These children might now be recognised as having classic autism (see Frith, 1991). Wing & Gould (1979, cited in Bowler, 1992) first conceived of the ‘triad of impairments’ in autism consisting of impairments in socialisation, communication and imagination. Children were observed to vary in the severity of their impairments within this triad, hence the notion of an ‘autistic spectrum’ (with disorders lying within the spectrum known as Autistic Spectrum Disorders or ASDs). Inherent in this spectrum is the notion of a continuum of severity, with extremely impaired functioning at one end, and high functioning autism (HFA) at the other. Some would regard HFA and AS as one and the same, whilst others have emphasised the distinctions (e.g. see Rinehart, Bradshaw, Brereton & Tonge, 2002; Blacher, Kraemer & Schalow, 2003). It is beyond the scope of this essay to further explore this contentious issue, however the author will attempt to clearly specify whether the research under consideration is specific to AS or to autism in general.

In the following essay the concept of developmental pathways, and research on neurodevelopment will first be considered, under the heading of ‘developmental theories’. Then Theory of Mind (ToM), the Executive Dysfunction Account and Central Coherence Theory will be considered under the heading of ‘psychological theories’. Finally the implications for assessment and intervention will be outlined, and diversity issues will be considered.
Developmental Theories

Developmental Pathways

Szatmari (unpublished paper, cited in Szatmari, 2000) carried out a factor analysis of 129 children with autism and AS, and identified two independent dimensions: severity of symptoms, and level of functioning. He proposed that since these dimensions were not correlated, caution should be exercised in interpreting ASD as lying along a single continuum of severity. He suggested that instead of regarding these disorders as lying along a continuum, they should be conceived of in terms of different developmental pathways. Evidence for this is provided by a series of studies in which the development of children with HFA and AS has been tracked over time (e.g. Szatmari, Archer, Fisman, Streiner & Wilson, 1995; Szatmari, Bryson, Boyle, Streiner & Duku, 2003). One group consisting of children with HFA, and one group of children with AS (distinguished from the HFA group by the absence of clinically significant language delay). Measures of language and non-verbal skills were taken at 4-6 years, and outcome measures (adaptive behaviour scales for socialisation and communication and a composite measure of autistic symptoms) were administered at 6-8 years and 10-13 years. At time 2, a subgroup of children who had been classified as autistic at time 1 showed the same level of language ability as those with AS had at time 1. This subgroup were also found to have similar abilities with regard to communication and socialisation as the AS group, hence they appear to have ‘caught up’ with their more able counterparts. Szatmari et al. proposed that the development of language seems to have enabled this subgroup of autistic children to have moved from one developmental pathway, the autism pathway, to another, the AS pathway. Szatmari et al. (2003) noted two variables, IQ and language development, were the best predictors of outcome; those children who had relatively higher IQ’s and who had developed functional language before the age of 6 years had a better outcome.

Neurodevelopment

Folstein & Rutter (1977, cited in Bailey, Phillips & Rutter, 1996) first demonstrated a strong genetic component in autism. Rinehart et al. (2002) propose that the genetic link is even more prominent in AS than in autism. The hereditary component to autism and AS suggests an organic basis for the disorders, and there is some evidence
to suggest that the brains of children with AS may develop differently to those of other children. In particular, there is evidence to suggest that the fronto-striatal brain region may be damaged in those with AS. McAlonan et al. (2002) note that people with autism are believed to have a deficit in ‘sensorimotor gating’. This leads to information overload, and can account for the inability to prevent repetitive thoughts and actions. Sensorimotor gating can be measured using ‘prepulse inhibition of startle’ (PPI), the idea being that a startle response to a strong stimulus is inhibited by a weak stimulus occurring immediately before it. Impairment of sensorimotor gating can be inferred from the size of the PPI measure. The limbic circuitry, and in particular fronto-striatal regions, are believed to form the biological substrate of sensorimotor gating. McAlonan et al. sought to find out whether people with AS would demonstrate impaired sensorimotor gating compared to controls, as measured by PPI, and whether there would be any differences with regard to brain anatomy between those with AS and controls, as measured using MRI. The PPI response was impaired in those with AS compared to the control participants, suggesting an impairment in sensorimotor gating in AS. MRI revealed significantly less grey matter in fronto-striatal and cerebellar regions in those with AS, and widespread differences in white matter between the two groups. The cerebellar damage was understandable given that the fronto-striatal regions have close links with the cerebellum.

With regard to the white matter differences, the authors note that one area of reduced white matter in the brains of those with AS was the left superior lobe temporal speech area. This is consistent with Szatmari’s contention that the development of language is crucial in determining which developmental pathway will be followed; those who develop language normally will move along the higher functioning, AS pathway according to his model. Although speech develops normally in those with AS, the use of speech may strike one as rather pedantic and ‘odd’, and it is possible that the white matter differences identified in this study contributes to this.
Psychological Theories

Theory of Mind

Gutstein & Whitney (2002) note that the failure to develop social competence despite normal development of language is a hallmark of AS. They also note that a core feature of this lack of social competence is a lack of 'experience sharing'. The failure of the young autistic child to initiate joint attention with the caregiver by pointing at an object and looking at them, would appear consistent with this. According to Asher, Parker & Walker, (1996, cited in Gutstein & Whitney, 2002), the most typical form of experience sharing relationship is friendship. Slomkowski & Dunn, (1996, cited in Gutstein & Whitney, 2002) propose that successful friendship is predicted by the sophistication of a child’s ‘Theory of Mind’ (ToM). ToM refers to the ability to make inferences about the mental states of others, and to understand and predict their behaviour on the basis of these inferences (Frith & Happe', 1994).

Research has shown that those with autism often lack ToM, with the result that they do not understand that others can hold false beliefs about the world and that their behaviour can be predicted by these false beliefs, rather than by external reality (Bowler, 1992). Bowler (1992) aimed to replicate earlier findings of impaired ToM in people with autism, using participants with AS. The study included two sorts of ToM task, first-order, in which the person with AS needed to show understanding of another’s mental state and make inferences about their behaviour based on this, and second-order, in which the person with AS needed to show understanding of another’s mental state concerning a second person’s mental state, and make inferences about the first person’s predictions of the second person’s behaviour based on their understanding. There were three groups of participants, those with AS, and two control groups; chronic schizophrenics with social impairment and controls without impairment. The overall findings showed that those with AS were not impaired on first or second-order ToM tasks. Bowler (1992) highlighted this paradoxical finding — why should those with AS show successful performance on ToM tasks, and yet be unable to engage in successful social interactions in real life?
Kaland et al. (2002) attempted to address this issue. They argued that one problem with conventional ToM tasks (such as those used by Bowler) were that they lacked ecological validity. Indeed Bowler's first ToM test scenario involved two children and an ice-cream van. Bowler failed to report the mean age of his 'normal' control group, but the mean ages of the AS and schizophrenia groups were 27 and 46 years respectively. The ice-cream van scenario would therefore seem rather simplistic and age-inappropriate. Kaland et al. attempted to overcome the problem of low ecological validity by using stories about everyday situations, such as an architect's plans for a new building, and a story about a girl's allergy to her family's dog. In addition to examining the effects of using a more naturalistic context, the authors wanted to ascertain whether those with AS would be better at inferring physical than mental states. They predicted that those with AS (n=21) would take longer to answer the questions than an age-matched control group (n=20), especially those about mental states. It was found that those with AS were significantly slower than the control participants at inferring physical states, and even slower at inferring mental states. A criticism of their procedure is that they routinely administered the questions about physical states before those about mental states. Therefore practice effects may have meant that those with AS were slow, but ultimately successful at the 'harder' questions about mental states, because they had become used to the basic exercise. The findings from both Bowler (1992) and Kaland et al. (2002) are puzzling in that those with AS were able to successfully infer another person's mental state and make successful predictions about their behaviour based on this, and yet they show marked impairment in social interactions in real life. One explanation for this is Hermelin & O'Connor's (1985, cited in Kaland et al. 2002) 'Logi-co-affective state' theory. According to this theory, people with AS use cognitive processes to solve problems that ordinarily would be solved using our emotions. According to Bowler, (1992) this means that people with AS can succeed on ToM tasks, but in real life social situations their 'cognitive' approach results in a disruption in the pattern of timing of conversations, with the result that they appear 'odd'.

ToM has a number of strengths. For example it is parsimonious in that it accounts for both communication and socialisation problems in autism in terms of a single impairment (Bailey, Phillips & Rutter, 1996). It also has 'high fertility' in that it has
acted as a springboard for a vast number of research studies. However its explanatory power in the domain of autism and AS is limited. For example Leslie (1990) proposed that one of the fundamental skills constituting ToM is shared pretence. Shared pretence is often demonstrated through symbolic play. Bowler (1992) notes that given the apparent interdependency of ToM and symbolic play, we would not expect ToM to be demonstrated by a child who cannot engage in symbolic play, or vice versa. However, Bowler cited a study by Lewis & Boucher (1988) who found evidence of symbolic play without ToM and vice versa (it would appear, however, that Lewis & Boucher inferred ability to engage in symbolic play when young by asking parents whether their child currently has an interest in fiction — thus undermining the credibility of their findings).

Volkmar (1996, cited in Rinehart et al. 2002) also questioned the validity of ToM by pointing out that children with autism start to demonstrate social problems before ToM would be expected to develop, implying that lack of ToM is not the cause of impaired social competence. Another criticism of ToM is that it offers no explanation for the repetitive and obsessive behaviours often demonstrated by those with autism and AS (Jolliffe & Baron-Cohen, 2002). In addition, ToM has no clear biological underpinnings. Bailey et al. (1996) note that there is a lack of evidence for localised brain lesions accounting for specific ToM deficits. Bailey et al. also note the similarities between behaviours shown by those with autism and behaviours of people with frontal lobe lesions, and the similarities between performance of these two groups on tasks of executive functioning — both those with frontal lobe brain damage and those with autism tend to perform poorly on tests of executive function.

**Executive Dysfunction Theory**

McAlonan et al. (2002) propose that in AS, the cognitive mechanism through which impaired sensorimotor gating (at a neurological level) leads to repetitive thoughts and actions is impaired inhibitory function. Specifically, they suggested that impaired sensorimotor gating results in difficulties with inhibiting unnecessary thoughts and actions, resulting in the person with AS displaying repetitive and ritualistic behaviours. Thus impairment in executive function (specifically a deficit in inhibitory processes) may be an underlying component of AS. The executive dysfunction
account certainly offers a clear, precise explanation for the repetitive behaviours observed in AS, with well-evidenced neurological correlates (i.e. the fronto-striatal brain region, see McAlonan et al. 2002).

However, the executive dysfunction account is unable to offer specific explanations for the particular impairment in reciprocal interaction shown by people with AS (Jolliffe & Baron-Cohen, 2001). Neither can it account for the particular pattern of cognitive strengths shown by people with autism and AS on some tasks, such as the Block Design subtest of the Wechsler IQ tests (Shah & Frith, 1993, cited in Mottron, Burack, Iarocci, Belleville & James, 2003) or tasks involving identification of embedded figures (Jolliffe & Baron-Cohen, 1997, cited in Mottron et al. 2003). In fact, ToM is also unable to account for this pattern of strengths.

The insufficient explanatory power of both ToM and the Executive Dysfunction Theory has led to the development of a more contemporary theory, discussed below.

**Central Coherence Theory**

Frith (1989, cited in Jolliffe & Baron-Cohen, 2001) proposed that people with autism don’t integrate information in the quest to obtain meaning like non-impaired individuals do. She claimed that this failure to integrate information in order to ascertain meaning results in a tendency for local over global processing. She termed this ‘Weak Central Coherence’ (WCC). It is proposed that this local preference can explain the superior performance of people with autism on tasks such as block design and embedded figures, since both tasks require one to suppress processing of the global figure in order to focus on the local elements. It is argued that for most people global processing takes precedence, but not for people with autism, who therefore demonstrate superior performance compared to their ‘normal’ counterparts.

Jolliffe & Baron-Cohen, (2001) wanted to find out whether people with HFA and AS can integrate information in order to ascertain meaning but just prefer not to. They also wanted to identify whether a preference for local processing goes hand-in-hand with impaired global processing (whether the two are inversely related). There were three groups of participants: 17 with HFA, 17 with AS and 17 ‘normal’ control.
participants. In the first experiment participants were presented with sheets of paper, each containing five stimuli. Participants had to integrate the stimuli ‘in their mind’s eye’ to make a coherent scene. They were also required to identify the odd stimulus, and this task acted as a check to ensure that the stimuli had been successfully integrated (the integration condition). They were also given a further control task that was thought not to load heavily on integration abilities; identifying the ‘odd-on-out’ from five separate items. Both autism and AS groups were significantly slower than controls at identifying the odd-one-out in the integration condition. In addition, those with autism identified the odd-one-out wrongly significantly more times than controls for four separate scenes in the integration condition, suggesting that they may have difficulty with integration per se. However those with AS made significantly more errors than controls for just one scene. The results offer support for the contention that those with AS can integrate information to glean meaning but perhaps find this difficult, hence their longer response times compared to control participants. The second experiment aimed to find out whether local and global processing were inversely related in those with autism and AS. Participants were presented with stimuli already integrated into coherent scenes. There were three tasks, each corresponding to a different condition: describing the scene (description condition), give the type of scene, and identify the inappropriate object (context-sensitive condition, thought to require integration of information to give contextual meaning), and locate an already named ‘odd’ object on the page (location condition). It was predicted that those with HFA and AS would be less able to appreciate the integration of objects in context in order to identify the type of scene, and the odd object, than controls. In contrast, the clinical groups were expected to be quicker than controls at identifying the location of a named object by virtue of their tendency to focus on local detail. Those with HFA and AS were not found to be quicker than controls in the location condition. However, relative to controls, both clinical groups were significantly impaired at identifying the type of scene, and the HFA group was impaired at identifying the odd object. Jolliffe & Baron-Cohen (2001) concluded that their study yielded some evidence in support of WCC in those with HFA and AS, but that there was no evidence to suggest the co-occurrence of weak global processing and enhanced local processing.
Happe’, Briskman & Frith, (2001), sought to find evidence for WCC among the parents and male siblings of boys with autism (presumably they focused on males because autism and AS are more prevalent in males than females — e.g. ratio of 4:1 for AS, Ehlers & Gillberg, 1993, cited in Rinehart et al. 2002). They noted the evidence for a genetic component in autism, and that such evidence had spurned a proliferation of research to identify an ‘autistic phenotype’. According to Happe’ et al. researchers have largely restricted their search to behavioural similarities, to identify a behavioural phenotype. Therefore they aimed to find evidence for a cognitive phenotype, and employed WCC as the theoretical basis for the phenotype. They proposed that the degree of central coherence exhibited by individuals in the normal population varies along a continuum from weak to strong. They also argued that this forms an individual’s ‘cognitive style’, and is not usually problematic. However if WCC as a cognitive style is coupled with a deficit in ToM, (as in autism and AS) this results in impaired functioning (Happe’ et al. 2001). The authors predicted that the first-degree relatives of children with autism would show WCC. They carried out two studies, one aimed at identifying evidence for WCC on tasks requiring processing of local detail, and another aimed at relating WCC to non-social preferences in everyday life (Happe’ et al. 2001 and Briskman, Happe’ & Frith, 2001 respectively).

In the first study, fathers and brothers of boys with autism, boys with dyslexia and non-impaired boys were given various tasks requiring attention to be focused on the local elements rather than the global whole, including a visual illusion that involves a comparison of the size of two circles that are actually the same size. One appears larger than the other if processed globally, but not if local processing takes place. Fathers were found to show a preference for local processing, but siblings were not, a finding that is difficult to explain. The second study involved a questionnaire, including items based on ToM to elicit information about social preferences, and items based on Central Coherence Theory to elicit information about non-social skills. Parents completed an adult version of the questionnaire for themselves and a child’s version for their sons. The reliability of parental self-reports in this study may be questionable. Also of concern is the authors’ admission that items were discarded if few respondents gave the ‘target’ response — surely such a process would result in
the findings being biased in favour of the authors' hypotheses? Aside from these limitations, responses to the questionnaires indicated that fathers generally preferred solitary activities and were interested in detail and sensitive to minor changes. Social preferences of the children were also consistent with autism. The authors interpreted their findings as suggestive of a broad cognitive phenotype for autism characterised by WCC (Happe' et al. 2001) and that this cognitive phenotype is also evident in real life in terms of social and non-social preferences of the fathers of autistic boys (Briskman et al. 2001).

Central Coherence Theory has explanatory power in terms of its ability to account for the particular pattern of cognitive strengths and weaknesses of people with autism and AS. However it cannot offer a specific explanation for the socialisation and communication problems found in these disorders. Another criticism of the theory is that it seems to be able to explain every eventuality and is therefore difficult to falsify. For example Jolliffe & Baron-Cohen (2001) included a control task in their first experiment, which was supposed to check that participants were capable of identifying the 'odd-one-out' when not required to integrate stimuli. However the authors pointed out that the task would need some degree of integration ('coherence') since it requires objects to be grouped so as to identify the odd one. They accounted for this by proposing that previous evidence has shown that those with AS and autism should have sufficient coherence to cope with this task (Ungerer & Sigman, 1987, cited in Jolliffe & Baron-Cohen, 2001). A problem with Central Coherence Theory is that it can be seen to apply in some way to many tasks, with the consequence being that authors are left to explain away seemingly contradictory assumptions using somewhat unconvincing arguments. This ultimately threatens the theory's integrity.

Another possible criticism of Central Coherence Theory is the finding by Mottron et al. (2003) of intact global processing in adolescents with HFA. Frith (1989, cited in Jolliffe & Baron-Cohen 2001) claimed that people with autism don’t integrate information in order to gain meaning. The implication of this is that global processing is impaired in those with autism, but Mottron et al.'s finding casts doubt on this assumption. Navon (1977) showed that in healthy participants processing of the global object takes precedence over processing of local features (thus global
processing occurs first) and global processing can take place without interference from local features, but not vice versa. He labelled this phenomenon 'global precedence'. Rinehart, Bradshaw, Moss, Brereton & Tongue (2000) demonstrated that people with HFA and AS are not impaired at global processing per se, but they are more vulnerable to interference from incongruent local stimuli than healthy controls. Therefore, their information processing style reflects a lack of global precedence. Rinehart et al. propose that in non-impaired individuals, once the global feature has been identified, further local processing becomes redundant and thus ceases. However in those with autism or AS, unnecessary processing of local features continues because of an inhibition deficit. Therefore Rinehart et al. attribute the global/local processing differences shown by those with autism and AS not to WCC, but to executive dysfunction.

Implications for Assessment and Intervention

Assessment

As noted in the introduction, AS can be manifested in a number of cognitive and behavioural characteristics — for example impairment in reciprocal interaction, odd use of language, or repetitive and ritualistic behaviours. Certain theories would seem better at explaining some symptoms than others. Therefore, the primary aim of an assessment might first be to identify which particular symptom presents most of a hindrance to the individual's everyday functioning, so that the appropriate theory can then be used to guide further, more specific assessment and intervention.

For example, if the initial assessment highlights particular problems with reciprocal interaction, further assessment using ToM tasks may take place. Research has shown that such tasks would need to be as naturalistic as possible to provide a more accurate reflection of impairment in everyday functioning.
Intervention

Developmental Pathways
Following the findings of their series of studies, Szatmari et al. (2003) recommend early intervention to facilitate the development of language. It is clear how this might apply to children identified as progressing along the autistic pathway, since early intervention to facilitate language development should have the effect of transferring them across to the more able AS pathway. What is less clear is how an intervention based on facilitation of language development might be applied to help children with AS to move onto a ‘normal’ developmental pathway, since by definition, these childrens’ language development is not delayed. What is unusual is their pedantic and literal use of language. One can speculate that the absence of ToM may underlie this characteristic, since a phrase may be understood in a literal sense if one has little awareness of ‘where the other person is coming from’, as might occur if one did not possess a ToM. Therefore an intervention drawn from ToM may be most suitable in attempting to modify the unusual usage of language by a child with AS.

Neurodevelopment
If the impairments associated with AS were attributed fundamentally to brain abnormality, then the suggested intervention would be a pharmacological intervention to modify neurotransmitters in an attempt to counter the effects of the abnormality. Bailey et al. (1996), in a review of the evidence, concluded that no drug has a particularly beneficial effect in autism or AS. However more recently Raheja, Libretto & Singh, (2002, cited in Blacher, Kraemer & Schalow, 2003) found that risperidone reduced frustration and anxiety in those with AS. Hence it would appear that this drug is working to reduce the negative emotional effects of living with AS, rather than tackling the underlying problematic symptoms themselves.

ToM
Gutstein & Whitney (2002) propose that an intervention should be geared towards providing the person with skills so that they can engage in experience sharing relationships. Such an intervention might facilitate the development of a sound ToM. According to these authors, there are a number of problems inherent in trying to
intervene to develop such skills. For example in trying to motivate the person to engage in the intervention program, experience sharing occasions must be made pleasurable. However, as the child gets older, the ratio of rewarding experience-sharing relationships to rewards from other experiences will become heavily skewed in favour of reliance on other experiences for reinforcement. Another difficulty lies in generalising skills learned during intervention sessions. This is problematic both because skills may lack meaning for the individual as they are being taught outside of their developmental context, and because the skills of peers are likely to be far more advanced, thus peers may be unsympathetic regarding the person’s attempts to practice their recently acquired skills (Gutstein & Whitney, 2002).

**Dysexecutive Theory**

Given that the evidence for executive dysfunction is highly interrelated with that for abnormal brain development, proponents of the executive dysfunction account might suggest pharmacological treatment. Indeed, drug treatment has been found to be successful in the treatment of Tourettes Syndrome, a disorder characterised by inhibitory deficits. Therefore it is possible that the repetitious and ritualistic behaviours shown by people with AS (that have been largely attributed to executive dysfunction) may be treated successfully by drugs.

**Central Coherence Theory**

It is hard to draw recommendations for intervention from the WCC hypothesis, and this could represent a serious threat to the theory’s utility. A reason for this may be that researchers have conceived of WCC as being part of a dimension of Central Coherence along which the ‘normal’ population varies. Therefore WCC is not necessarily regarded as pathological, in contrast to delayed language development, brain abnormality, an absence of ToM or executive dysfunction, all of which are relatively easily classified as ‘abnormal’. Happe’ et al. (2001) proposed that WCC produces impairment when coupled with a lack of ToM. This would suggest that WCC should not in itself be a target for intervention. Rather intervention should be tailored towards developing a person’s ToM.
Diversity Issues
Several researchers have claimed that AS could be regarded as a normal personality variant. This raises ethical implications with regard to whether one should intervene in order to 'help' a child with AS, who may be too young to give informed consent. Molloy & Vasil (2002) suggest that AS has been socially constructed by the education system and is perhaps more helpful to this system than to the individuals who are labelled. With regard to WCC, cross-cultural studies have revealed differences between cultures with regard to visual perception. The finding of the low susceptibility of members of African tribes to illusions (e.g. Segall, Campbell & Herskovitz, 1963, cited in Gross, 1996) would appear consistent with a preference for local processing, or WCC. It is interesting to ponder on whether ToM deficits exist in such cultures, and if so, whether WCC plus lack of ToM means that the person is regarded as 'abnormal'. Finally with regard to diversity, phenotype research has revealed similarities between autistic boys and their fathers. The implication of this is that autistic and AS-like characteristics are likely to be accepted and perhaps valued within a person's family culture.

Conclusion
To conclude, evidence regarding neurodevelopment, executive functioning and WCC in AS implies a degree of overlap between these three theories, making them more compelling. ToM has high explanatory power but is weakened by a lack of evidence regarding neurological underpinnings. Each theory offers its own perspective on the characteristics of AS, and each should perhaps be used in a way that promotes optimum benefit for the individual concerned.
References


Critically evaluate the contribution of Cognitive Behaviour Therapy to helping with problems of anxiety and depression in older people

Working with Older People Essay
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Year Two
Introduction

Gallagher-Thompson & Thompson (1996) cite several reasons why a person might seek or be referred for help in later life, such as loss of a loved one, changes to physical health, or the change in lifestyle brought about by retirement. Older people may react to such changes by feeling anxious and/or depressed.

Gurland, Cross & Katz (1996, cited in Thompson, Coon, Gallagher-Thompson, Sommer & Koin, 2001) note that the prevalence of depression in older people in the community is as much as 15 – 20%, and Laidlaw (2001) suggests that depression is the most common psychiatric disorder in older people. Depression can accompany dementia, with 20% of people with Alzheimer’s disease exhibiting depressive symptoms. Prevalence rates for anxiety symptoms in older people are also high, ranging from 10% to 20% in the community (Fuentes & Cox, 1997; Wisocki, 1994, both cited in Barrowclough, et al. 2001).

Overall, there is a dearth of literature evaluating the efficacy of psychological treatments for older people, relative to that available for younger people (Carmin, Pollard & Ownby, 1999). Woods (2003) notes that the National Service Framework (DOH, 2001) emphasised the importance of provision of adequate healthcare for older people to ensure that they are not discriminated against. Despite this, GPs may fail to offer older people treatment for psychological problems (Laidlaw, 2001) because of the misguided belief that it is only natural to feel depressed when one gets older.

In the following essay the author will begin by briefly discussing the reasons for the preference amongst GPs to prescribe medication rather than psychological therapy as this has a direct impact on the potential of Cognitive Behaviour Therapy (CBT) to contribute to the treatment of psychological problems in older people. She will then critically evaluate the contribution of CBT to helping with problems of anxiety and depression in older people, including consideration of: evidence from randomised controlled trials and the limitations of this evidence; the debate regarding whether or not adaptations / modifications to ‘standard’ CBT (i.e. Beck, Rush, Shaw & Emery, 1979, cited in Scholey & Woods, 2003) are necessary; the apparent tension between the need to keep the older person focussed during CBT treatment sessions
versus conveying respect for the older person’s life experience. It will be assumed that the reader is familiar with the theoretical underpinnings of CBT and the associated techniques as detailed explanation of these issues is beyond the scope of the present paper.

**GPs’ preference for Medication over Psychological Interventions**

The most dominant form of treatment for older people presenting to primary care settings with symptoms of anxiety and/or depression would appear to be drug therapy (Gallo, Ryan & Ford, 1999, cited in Landreville, Landry, Baillargeon, Guerette & Matteau, 2001; De Beurs et al. 1999, cited in Barrowclough et al. 2001). Several reasons for this have been proposed. For example the lack of a sufficient evidence base for psychological therapies as opposed drug therapies (underpinned by insufficient funding for psychological therapy trials relative to that provided by drug companies for drug trials – Arean & Cook, 2002). There is also the belief that older people do not possess the cognitive capabilities necessary to benefit from CBT, which stems from Freud’s proposal that older people cannot change due to the inflexibility of their cognitive apparatus (Woods, 2003). Doubleday, King & Papageorgiou (2002) found evidence to dispute this belief. They noted that fluid intelligence is thought to underlie abilities such as problem solving and abstract reasoning (e.g. Knight & Satre, 1999 cited in Doubleday et al. 2002), abilities thought to be necessary for engaging in CBT. They also noted that fluid intelligence can decline with age (Hayship & Stern, 1979, cited in Doubleday et al. 2002). However in their sample of 16 older adults with anxiety disorders engaging in CBT (mean age 69 years) they found no relationships between fluid intelligence and ability to benefit from CBT, suggesting that older adults are able to benefit from CBT. Another contributory factor is the belief that older adults prefer medication to psychological treatments. However this belief has also been questioned – Landreville et al. (2001) presented 200 people (mean age 73 years) awaiting appointments at GP clinics with hypothetical vignettes depicting a person with either mild/moderate, or severe depression. Participants rated cognitive therapy as more acceptable that antidepressants if the depression was only mild/moderate.
Psychological therapies may in fact become increasingly popular because of the increased risk of side effects and complications in older people. This is due to the likelihood that they will be taking multiple drugs for physical ailments, and the likelihood that changes in reactions to drugs will occur with advancing age (Carmin et al. 1999; Wengel, Burke, Ranno & Roccaforte, 1993, cited in Stanley et al. 2003b).

In summary, GPs appear to prefer to prescribe medication for older people presenting with problems of anxiety and depression, rather than referring them for psychological treatment such as CBT. The next section will look at whether this is justified given the evidence base for CBT as an effective treatment for anxiety and depression in older adults.

The ‘Hard’ Evidence – Randomised Controlled Trials (RCTs)

Chambless & Hollon (1998, cited in Kneebone & Dunmore, 2000) propose that psychological interventions should only be regarded as empirically supported if RCTs reveal their statistical superiority relative to other treatments or to no treatment at all.

As regards depression, Thompson et al. (2001) conducted a RCT to evaluate the efficacy of Desipramine (a tricyclic antidepressant), CBT, or Desipramine and CBT combined, in the treatment of older people (N = 102; mean age 67 years) with a diagnosis of major depressive disorder. In terms of outcome, the main finding was that Desipramine and CBT combined produced statistically superior outcome relative to Desipramine alone, with CBT alone still out performing Desipramine alone, although to a lesser extent that in the combined condition, since the Hamilton (1967, cited in Thompson et al. 2001) Depression Scale ratings for participants receiving CBT alone did not show statistically significant improvement over those of participants receiving Desipramine alone.

As regards anxiety, Barrowclough et al. (2001) conducted a RCT to evaluate the efficacy of CBT relative to supportive counselling for anxiety disorders in older people (N = 55; mean age 72 years). Outcome as measured by self-report measures (e.g. Beck Anxiety Inventory) and observer rating scales (e.g. Hamilton [1959, cited in Barrowclough et al. 2001] Rating Scale for Anxiety) showed statistically significant
reduction in anxiety scores for the CBT group relative to the supportive counselling group both immediately post-treatment and at follow-up (up to 12 months). Stanley et al. (2003a) conducted a small RCT (N = 12, mean age 71 years) to compare the efficacy of CBT relative to ‘usual care’ (a weekly phone call to assess symptom severity) in older people with a diagnosis of Generalised Anxiety Disorder (GAD) in a primary care setting. Symptoms were significantly reduced post-treatment for those receiving CBT, but not for those receiving usual care. Stanley et al. (2003b) conducted a RCT to evaluate the relative efficacy of CBT relative to a ‘minimal contact’ control group (weekly phone call to assess symptom severity) in older people with GAD (N = 85, aged 60 or over). They found that those receiving CBT obtained statistically significant improvements in measures of anxiety, depression and quality of life relative to those who received minimal contact.

In summary, the RCTs reviewed above appear to suggest that CBT has received some empirical support as an efficacious treatment of anxiety, at least. The case for depression is less clear, with Thompson et al. ’s (2001) study appearing to suggest that the optimal treatment for depression may be a combination of CBT and drug therapy.

However Kendall (1999 – cited in Barrowclough et al. 2001) notes the importance of clinical significance rather than mere statistical significance of findings if the outcomes of RCTs are to be considered meaningful, and Laidlaw (2001) questions the applicability of findings of RCTs to the real-world context. Indeed, authors of various meta analyses have pointed out the lack of generalisability of RCT findings since the participants are often white, middle class, well-educated and therefore not representative of older people typically found in primary care (e.g. Stanley et al. 2003b; Thompson et al. 2001). Although there are exceptions (e.g. Stanley et al. 2003a; Barrowclough et al. 2001) the situation is not helped when researchers examining the efficacy of CBT in primary care settings fail to provide an adequate description of their participants in terms of mean age, level of education or ethnicity (e.g. Walker & Clarke, 2001).
Are Adaptations to 'standard' CBT necessary when working with older people?

Zeiss & Steffen (1996, cited in Laidlaw, 2001) draw a distinction between treatment modifications, which they claim are designed to improve treatment outcome within a particular therapy model, and treatment adaptations, which they claim should urge the clinician to exercise caution since the model they have chosen may be inadequate. However since this distinction has apparently not been widely adopted in the literature, with many researchers still appearing to use the two terms interchangeably (e.g. Scholey & Woods 2003) the terms will be used interchangeably in this paper.

Some authors propose that adaptations to standard CBT are necessary when working with older people because of the cognitive changes and sensory impairments that often occur with advancing age. Dementia may be seen as an extreme form of this cognitive impairment, and some suggest that alternative forms of therapy other than CBT may be preferable when the older person has dementia, such as Interpersonal Therapy (James, Postma & Mackenzie, 2003) or Reminiscence Therapy (Baines, Saxby & Ehler, 1987, cited in Arean & Cook, 2002). However others have shown that people with dementia can still benefit from CBT (e.g. Scholey & Woods, 2003). Although dementia may be regarded as an extreme form of the cognitive impairment sometimes seen in older people, 58% of older adults over the age of 65 years have some level of memory impairment (Crook & Larabee, 1988, cited in Secker, Kazantzis & Pachana, 2004). With regard to the structure of CBT sessions, Secker et al. (2004) note the particular importance of 'session bridging' (review of issues raised during the interim between sessions and linking of issues to material covered in the previous session) if the older person has memory impairment. Mohlman et al. (2003) compared the relative efficacy of standard CBT with enhanced CBT for older people with GAD (N = 42, age range 60 –79 years). Enhanced CBT included memory aids designed to increase the participants' ability to remember techniques and to complete their homework. Those in the enhanced CBT group showed greater improvement than those in the standard CBT group.

Gallagher-Thompson & Thompson (1996) note that when working in a CBT framework with older people, information should be presented to multiple sensory modalities to allow for sensory impairment. However, in the case of older people with Obsessive Compulsive Disorder (OCD) caution should be exercised in disentangling
what are the client’s attempt to cope with a genuine sensory impairment versus what may actually be part of the OCD (Carmin et al. 1999). For instance Carmin & Wiegartz (2000) cite the case of Mr X, an inpatient being treated for OCD. He repeatedly asked the nurses on the ward questions, and claimed this repetition was necessary as he couldn’t hear. However his hearing was tested and no impairment was identified, leading to the conclusion that his repeated questioning was part of his obsession for gaining information.

Carmin, Pollard, Ownby (1999) also note the possible need for modification of stimulus exposure exercises in the case of CBT for anxiety disorders in older people. They cite the case of Mrs P who had Chronic Obstructive Pulmonary Disease. They had to modify the usual breathing exercises used as part of their Exposure and Response Prevention component of CBT for OCD, in order to allow for her physical impairment.

However, others have argued that to assume modifications are a necessity in order for CBT to be effective with older people is unhelpful. For example Laidlaw (2001) concludes that there is no evidence to suggest that adaptations are necessary for older people without cognitive impairment and to suggest that they are is unhelpful as it has led GPs to prescribe medication in favour of CBT, owing to their assumption that CBT is not relevant to older people. Furthermore, Barrowclough et al. (2001) did not include substantial modifications to their CBT package as a previous study (King & Barrowclough, 1991, cited in Barrowclough et al. 2001) had found that older people benefited from the same techniques as their younger counterparts. In summary then, although certain modifications/adaptations to standard CBT appear helpful they should perhaps be considered on an individual basis rather than as an assumed necessity.

Effect of Non-Specific Treatment Gains on Depressive Symptoms in Older People

Floyd & Scogin (1998) questioned whether the reduction in older peoples’ depressive symptoms as a result of CBT is really due to modification of dysfunctional attitudes. Rather, they found little evidence for a change in dysfunctional attitudes as a result of
CBT. Instead, they propose that the decrease in depressive symptoms in older people following CBT may be due to a reduction in hopelessness. Ilardi & Craighead (1994, cited in Floyd & Scogin, 1998) propose that such an initial reduction in hopelessness is due to ‘non-specific factors’ such as therapeutic alliance, and that specific CBT techniques contribute to the maintenance of a reduction in depression. Interestingly in Stanley et al.’s (2003b) study older people with GAD receiving CBT showed significant improvement over those receiving minimal contact (a weekly phone call). This suggests that the improvement seen in those with GAD receiving CBT was due to the CBT techniques themselves rather than non-specific factors. It might be tentatively suggested from this that non-specific factors account for a greater proportion of the improvement in older people with depressive disorders, relative to the proportion of improvement accounted for by non-specific factors in those with anxiety problems.

The possible importance of non-specific factors such as therapeutic alliance in the reduction of symptoms of depression and anxiety in older people leads us on to an interesting dilemma. Some of the apparent strengths of CBT include its time limited nature (sessions are often limited in number) and its emphasis on the setting of clear, concrete, attainable goals at the beginning of therapy, which then remain the focus of future sessions. Indeed, the time-limited nature of CBT may be considered a strong selling point when one considers the short-term cost of such therapy relative to other psychotherapies that are typically longer-term, such as psychodynamic therapy. The building of a therapeutic alliance and collaborative relationship between the therapist and client are deemed of up most importance if goals are to be met—and therein lies the potential problem. The literature often hints at the tendency of older people to want to reminisce and to talk in detail about previous life events and experiences during therapy sessions (Gallagher-Thompson & Thompson, 1996; Dick & Gallagher-Thompson, 1996, cited in Seeker et al. 2004). The extent to which this assumption is based on clinical experience or research evidence is unclear. However if there were any truth in the assumption, then the CBT therapist would appear to have a dilemma on their hands. How to reconcile the tension between on the one hand keeping the older person focused on treatment goals, but on the other hand, building and
maintaining a strong therapeutic alliance (which may necessitate the provision of time for the older person to speak about their life experiences).

**Tension between keeping the older person ‘focused’ versus conveying respect for their own life experiences**

In the literature, some authors emphasise the importance of devoting time to allowing the older person to talk about what they want to talk about, in the interest of building rapport. For example Floyd & Scogin (1998) mention that they allow for "chit chat" before and after CBT sessions, and interpret this as therapeutic social exchange rather than resistance from the older person, and Scholey & Woods (2003) allow for frequent discussion of ‘tangential’ and ‘peripheral’ topics as they feel this helps establish rapport. However other authors offer apparently conflictual advice, emphasising the need to keep the older adult focused and to not allow them to stray off the point. For example Zeiss & Breckenridge (1997, cited in Secker et al. 2004) note that agenda setting on a white board is especially important if the older person starts ‘story-telling’ and Dick et al. (1996, cited in Secker et al. 2004) claim that the therapist should not be afraid to interrupt the client if the discussion appears to be straying from the focus of the session.

To further complicate matters, Kraaij & de Wilde (2001 cited in Woods 2003) note how life experiences during childhood and adolescence can influence the occurrence of depression in later life, suggesting a need for the CBT therapist to have an understanding of the depressed older person’s previous life experiences. Indeed Scholey & Woods (2003) present the case of ‘Martha’ who successfully repressed memories of childhood abuse until her dementia meant that she know longer possessed the cognitive capacity to maintain such a defence mechanism, at which point she became depressed. Furthermore, Holden & Woods (1995, cited in Woods, 2003) suggest that when an older person has dementia, an understanding of their previous life experiences is important because it facilitates communication and may provide clues as to what underlies current behavioural and speech patterns. James et al. (2003) suggests that knowledge of the older person’s life experiences enables the
CBT therapist and the older person to gain insight into how they coped with adversity in the past.

In summary, it would appear important for the CBT therapist not to be overly concerned with keeping the older person focused on current goals, but rather to allow some time for the older person to talk about previous life experiences both in the interest of gaining and maintaining therapeutic alliance and because knowledge of previous life experiences may be essential to understanding the older persons' current difficulties and coping strategies that might be at their disposal.

**Cultural Awareness**

Being overly focused on an agenda and goals may be a mistake when working with older people within a CBT framework, not only because of the factors outlined above, but also because of the danger of being unaware of the older person's own cultural background and beliefs that may impact upon the efficacy of CBT/therapeutic process generally. For example Carmin et al. (1999) note that psychological problems may be seen as having particular stigma attached to them by older people. They also note that this stigmatised view can be problematic when the older person wants to seek help, for example such beliefs may make it harder for an older person with OCD to disclose the content of their obsessions. Indeed, Scholey & Woods (2003) found that two participants in their study wouldn’t complete a depression scale pre-treatment as they regarded it as too intrusive given the length of time they had known the therapist.

Aside from the importance of being aware of the attitudes and beliefs of the older person that may be characteristic of their particular cohort, the CBT therapist working within the primary care setting will need to be aware of cultural issues that may arise when working with older people from ethnically diverse backgrounds. For example Owusu-Bempah (2002) notes how confidentiality is a notion borne out of Western, individualist culture. Western values of confidentiality and privacy may be viewed as less important by older people from collectivist cultures, who may feel alienated from their families by the imposition of such a concept. The sons, daughters, brothers, sisters and grandchildren of the older person from a collectivist culture may too be confused and angered by the therapist’s attempt to adhere to the ‘confidentiality rule’,
and this will need to be dealt with sensitively. Furthermore some cultures have a different attitude to time. Whereas individualist cultures see time as limited and place great importance on the arranging of appointments and the use of schedules, collectivist cultures have a more laid back attitude to time (Hall, 1983) and Levine & Bartlett (1984, both cited in Owusu-Bempah, 2002). Owusu-Bempah (2002) notes that this will have implications for therapies that place importance on schedules and appointments and the notion of a time-limited collaboration (as does CBT). Therefore the therapeutic alliance and the efficacy of CBT may be greatly influenced by the older persons cultural background. It would thus appear imperative that the CBT therapist devotes enough time to allow the older person to talk about their background, both at the start of therapy and throughout the therapeutic process.

**Conclusion**

At first glance, the evidence base for CBT as an efficacious treatment of problems of anxiety and depression in older people appears rather compelling. However the limited generalisability of study findings is a serious limitation. Nevertheless, the literature suggests that CBT has made a significant contribution to helping with problems of anxiety and depression in older people. The issue of the applicability of CBT to older people certainly appears to have acted springboard for a young yet expanding body of research. The author’s greatest concern is the apparent tension between the need to maintain the older persons ‘focus’ on the agenda and goals as agreed in initial sessions, and the need to gain an insight into the older person’s life experiences and cultural background. She feels that the therapist should be guarded against rigid adherence to agendas and goals at the expense of gaining an insight into the older person’s cultural background and building rapport. This may appear particularly important in future studies, which should aim to evaluate the efficacy of CBT for older adults from ethnic minority backgrounds, as part of an attempt to increase the generalisability of findings. In such cases, the CBT therapist might need to be particularly careful not to impose their own assumptions about what are ‘tangential’ and ‘peripheral’ topics, or what should be classed as ‘straying off the point’. This is especially pertinent given that the therapist’s knowledge of the older person’s cultural background and life experiences will conceivably be limited.
References


CLINICAL DOSSIER
SUMMARY OF CLINICAL DOSSIER

An overview of the placements completed across the three years is included in this section, as is a summary of each of the five case reports undertaken. Case reports are selected to demonstrate experience obtained with clients of different ages, genders and cultural backgrounds. Case reports are also selected to demonstrate the application of a variety of theories and models. As with the essays, the case reports are presented in the order in which they were completed to show the development of my clinical skills over the three years.
Core Adult Mental Health Placement

Placement Details

Dates: October 2002 – March 2003
Supervisor: Dr Mike Tossell
NHS Trust: West Sussex Health & Social Care NHS Trust
Base: Princess Royal Hospital, Haywards Heath

Summary of experience

I carried out assessment and intervention work with six clients (two women and four men, aged 24 – 59 years). Referrals were made by the GP and clients were mainly seen in the GP surgery. Presenting problems included Bulimia, agoraphobia with panic disorder, tranquillizer addiction, sexual dysfunction and depression. Assessment and intervention work with these clients was predominantly conducted from within a CBT framework. In addition I conducted five neuropsychological assessments (three men and two women, aged 28 – 56 years). Presenting problems included memory impairment, attention impairment and deterioration in right hemisphere functions.

Since there was no opportunity for direct experience of CMHT work offered, I shadowed the Department’s CMHT Psychologist, including attending case review meetings and secure units to speak to clients with chronic schizophrenia and those caring for them.

Although there was no opportunity for group work within this placement, I was involved in the selection of potential candidates for referral to an anxiety management group to be run in another location.
Core People with Learning Disabilities Placement Summary

**Placement Details**

Dates: April 2003 – September 2003
Supervisor: Derek Blackburn
NHS Trust: East Sussex County Healthcare NHS Trust
Base: Community Learning Disability Team, Hastings

**Summary of experience**

I worked with ten clients (four men and six women aged 18 – 73 years). Assessment and intervention were based on a multi-element model that included aspects of CBT and systemic theories. I engaged in both assessment and intervention work with clients presenting with difficulties such as aggressive outbursts, hoarding behaviours, bereavement and self-injury. Intervention work often involved working closely with staff teams in the residential homes where clients lived.

Pure assessment work was also conducted. This included contributing to an assessment of a woman’s capacity to consent to the withdrawal of life prolonging treatment in the event of a worsening of her physical status, and conducting a prolonged assessment of a man with Fragile X Syndrome whose parents were struggling to care for him at home.

The work involved liaison with other members of the MDT, and attendance at weekly meetings focused on clients with challenging needs held by the Intensive Support Service within the CLDT. I was also able to complete a training course entitled ‘Strategies for Crises Intervention and Prevention.’
Core Children and Families Placement Summary

Placement Details

Dates: October 2003 – March 2004
Supervisor: Dr Hugh Milburn & Dr Ele Jones
NHS Trust: East Sussex County Healthcare NHS Trust
Base: CAMHS West Team, Hailsham.

Summary of experience

I worked with twelve clients at the placement base (six girls and six boys, aged 5 – 11 years). Presenting problems included dog phobia, bedwetting, and aggressive/disruptive behaviours. The model of intervention was integrative – mostly utilising a combination of Narrative and CBT techniques.

The work also included four psychometric assessments (WISC – III & WPPSI – R) with children aged 6 – 12 years. In addition I was involved in a weekly family therapy clinic, where I had the opportunity to observe the Family Therapist via a video link, be part of a reflective team, and lead some sessions.

Other opportunities included undertaking a piece of teaching – I held a formal teaching session for staff at a local school for children with emotional and behavioural difficulties. The teaching was about theories explaining Asperger’s Syndrome, and involved some role playing exercises. Other experiences included shadowing the ADHD Nurse, School Nurse and Health Visitor.
Specialist Narrative Therapy Placement Summary

Placement Details

Dates: April 2004 – September 2004
Supervisor: Margaret Henning
NHS Trust: West Sussex Health & Social Care NHS Trust
Base: Horsham Hospital, Horsham.

Summary of experience

I engaged in both assessment and intervention work with six individuals and one couple (one man, age range 18 – 58 years). Presenting problems included agoraphobia, OCD, depression, relationship difficulties, auditory hallucinations and self-harm. The difficulties of two of the clients could be categorised as severe and enduring and involved liaison with the CMHT with regard to risk issues.

There were also opportunities for joint assessments with my supervisor, which included more work with couples. In addition I conducted one neuropsychological assessment with a female client with memory problems.

During the placement I attended a fortnightly peer supervision group based on Narrative Therapy, during which I presented a case.

The placement provided the opportunity to further develop my interest in and experience of Narrative Therapy, through work with individual adults and couples in a primary care setting.
Core Older People Placement Summary

Placement Details

Dates: October 2004 – March 2005
Supervisor: Clare Crellin
NHS Trust: West Sussex Health & Social Care NHS Trust
Base: Linwood CMHC, Haywards Heath

Summary of experience

Assessment and intervention work was conducted with a total of eight clients (five women and three men, aged 69 – 82 years). Presenting problems included claustrophobia, problems with anger management, chronic pain and depression. This work included three clients who were seen for assessment only, one of which was seen for a neuropsychological assessment.

The work was conducted within a Psychoanalytic conceptual framework. Therefore assessments took the form of holistic structured interviews that were very comprehensive and could take place over several sessions.

This placement afforded the opportunity to develop my awareness of a range of psychoanalytic theories and approaches and how they could be applied to help older people with psychological difficulties.

I received joint supervision with a fellow trainee which increased opportunities for learning about this work. As part of the placement, I conducted two psychoanalytic observation sessions in different residential homes.
Specialist Neuropsychology Placement Summary

Placement Details

Dates: April 2005 – September 2005
Supervisor: Jo Johnson
NHS Trust: West Sussex Health & Social Care NHS Trust
Base: 16 Liverpool Gardens, Worthing

Summary of experience

I carried out neurorehabilitation work with seven clients in the community (three women and three men, aged 33 – 79 years). Presenting problems included a client with low mood and anxiety following acute Guillian Barre Syndrome, a client with disinhibited behaviour following head injury, and a client with excessive fatigue and Multiple Sclerosis.

In addition I conducted five neuropsychological assessments (clients were two males and three females, aged 23 – 42). Presenting problems included cognitive decline for which no organic cause had been identified, and memory problems following removal of a tumour from the right temporal lobe.

I was involved in the setting up of a group entitled “Coping with Multiple Sclerosis”. It was planned that I would co-run the group with the A Grade Psychologist, and I worked jointly with her to research and plan the sessions. In the event, there were too few referrals to justify running the group. However were other opportunities to gain experience of group work such as involvement with a local group for people with acquired head injuries.
Adult Mental Health Case Report Summary

Cognitive Behavioural Assessment and Treatment of a 33-year-old woman with Bulimia Nervosa

Presenting Problem

Diana, a 33-year-old woman of white British origin, was referred to the primary care Psychology service by her GP, having developed symptoms of Bulimia. Diana presented with symptoms of Bulimia Nervosa, including bingeing and vomiting up to five times a week. Her work in a local gym included taking several aerobics classes each week. Diana reported a “daily battle” with the urge to binge.

Assessment

Information for the assessment was gained through psychiatric reports, GP letters, interviews with Diana, monitoring sheets and psychometric instruments. Psychometric instruments included the Hospital Anxiety and Depression Scale (HADS, Zigmond & Snaith, 1983), the General Health Questionnaire (GHQ – 12, Goldberg, 1978) and the Eating Disorder Inventory – 2 (EDI – 2, Garner, 1991). Although Diana was not clinically anxious or depressed, her scores on three of the EDI subscales (“Drive for Thinness”, “Bulimia” and “Body Dissatisfaction”) were particularly high.

Formulation

Diana met DSM-IV (American Psychiatric Association, 1994) criteria for a diagnosis of Bulimia. Fairburn, Cooper & Cooper’s (1986) cognitive-behavioural model of Bulimia was used to explain the evolution and maintenance of Diana’s eating disorder. Diana appeared to ‘learn’ each of the various components that were serving to maintain the disorder, at various points throughout her life. For example Diana started to regularly overeat during her first pregnancy, when she would often be by herself in the evenings. This developed into a recurrent pattern throughout each subsequent pregnancy. Diana gained weight during her pregnancies. She recalled a wish to look more slim and attractive and said that she had no confidence in herself.
Body-image dissatisfaction is prevalent among bulimic patients (Garfinkel et al. 1992, cited in Polivy & Herman, 1993). Despite Diana’s body-image dissatisfaction she did not binge at this time. Instead she began to associate exercise with increased self-esteem.

Bingeing began some five years later. Bulimia patients frequently cite emotional distress as the cause of their binges (e.g. Elmore & De Castro, 1990, cited in Polivy & Herman, 1993). Diana recalled that she started to binge on Sunday evenings, after she had endured a stressful afternoon with her then partner and his child from a previous relationship. The onset of bingeing may also have been triggered by dietary restraint as Diana had started to deny herself certain foods. About one year after Diana had started bingeing, Diana began to vomit to avoid gaining weight following binges, signalling the presence of Bulimia.

**Intervention**

CBT was chosen as at the time of seeing this client it was believed to be more effective than other forms of psychotherapy in the treatment of Bulimia (see Wilson & Fairburn, 1998). The intervention took place over ten sessions, and was based on the treatment manual for Bulimia proposed by Fairburn, Marcus & Wilson, (1993). First, Diana was presented with the formulation in conjunction with the CBT model of the maintenance of Bulimia. One of Diana’s goals was to understand why she binged and vomited, and discussing the formulation and CBT model helped facilitate her understanding.

As part of the intervention Diana was asked to keep diary sheets of her eating habits and associated thoughts and feelings. However she often arrived at sessions without having completed the diary sheets. Being ashamed of eating habits is one reason why patients fail to self-monitor (Fairburn, Marcus & Wilson, 1993). Diana also found it very difficult to record troublesome thoughts and feelings on the diary sheets and a number of techniques were employed to help her with this, including asking her to complete homework tasks designed to invoke problematic thoughts such as looking at herself in a full-length mirror (see Fairburn & Cooper, 1989).
Another component of the intervention was to help Diana to develop a regular eating pattern (Fairburn, Marcus & Wilson, 1993). Upon initial presentation Diana was eating six small meals a day, since she believed in eating little and often. She was extremely reluctant to impose the eating plan on her life, therefore the intervention included a component of Motivational Enhancement Therapy (MET), since MET can increase motivation to change in patients with eating disorders (Feld, Woodside, Kaplan, Olmsted & Carter, 2001). Following this exercise, Diana agreed to adopt a regular pattern of eating.

Outcome

Episodes of bingeing and vomiting failed to reduce significantly. However by the end of therapy Diana had started to use the monitoring sheets to record problematic thoughts and feelings. She had also learned new skills in dealing with situations that may put her at risk of bingeing. In addition, her post-intervention psychometric measurement scores showed some improvement. For example had GHQ score no longer indicated psychiatric disorder, and her EDI – 2 “Bulimia” subscale score had decreased from 11 to 5.
References


People with Learning Disabilities Case Report Summary

Extended Assessment of a 28 year old man with Prader-Willi Syndrome who Presented with Aggressive Behaviour

Presenting Problem

Mr. Jones, a 28-year-old man of white British origin, was referred to the Psychology Team of the CLDS by the staff at the residential home where he lived. Mr Jones had a learning disability (LD) and Prader-Willi Syndrome (PWS). He had recently moved to the area and was reportedly feeling low and anxious and was prone to angry outbursts.

Assessment

During the initial assessment session Mr Jones described how he felt angry because personal items kept ‘going missing’. He described how when he discovered something was missing, he accused another resident of stealing it. Staff would then intervene and Mr Jones would become even more angry and be verbally aggressive towards the resident and other staff. Staff invariably later found the ‘missing’ item in Mr Jones’ room.

During the course of the initial assessment Mr Jones remarked that he was very anxious about his memory. However he appeared to view this as a separate issue.

Levels of anxiety and depression were assessed using the Beck Anxiety Inventory (BAI, Beck, 1990a) and a modified, version of the Beck Depression Inventory (BDI, Beck, 1990b) for use with people with LD. Mr Jones score on the BAI indicated severe anxiety and his score on the BDI indicated mild-moderate depression. Mr Jones completed the Anger Inventory from Benson’s (1986) anger-management package, and his pattern of scores indicated that he is angered by a wide variety of situations.
**Formulation**

Factors potentially contributing to Mr. Jones’ current difficulties appeared to span a range of levels. Therefore a multi-element approach was used for the initial formulation, as has previously been shown to be effective for people with LD (Grey, McClean & Barnes-Holmes, 2002). Mr Jones’ PWS and resultant LD were central to the initial formulation. PWS is a genetic disorder, and affected individuals usually exhibit certain behavioural/emotional/cognitive difficulties, including excessive eating, skin-picking and aggression.

The formulation also showed how aggression could arise due to staff’s style of interaction with Mr Jones. A family systems approach would suggest that the general style of staff communication toward Mr Jones further contributed to his aggression and low mood. Mr Jones’ cognitive difficulties could also contribute to his aggression and low mood. Dykens, de, Walsh *et al.* (1992, cited in Whitman & Greenswag, 1995) found evidence for short-term memory deficits in people with PWS. It was hypothesised that Mr Jones’ failure to locate personal possessions may originate from a memory deficit. Therefore further cognitive assessment was indicated. Mr Jones agreed with the initial formulation and appeared to understand the need for further assessment, focusing on his memory.

**Intervention**

Given the above formulation an extended assessment was conducted. ‘Everyday’ memory can be conceptualised in terms of three main processes; encoding, storage and retrieval (e.g. Cohen, 1996; Best, 1995). Memory failure could result from a deficit at any of these stages. However, given previous evidence suggesting and STM deficit, in PWS, and impairment at the stage of encoding was predicted.

A number of cognitive test instruments were administered to Mr Jones, over the course of ten sessions. This was in order to gain more information about both his general level of cognitive functioning and cognitive strengths and weaknesses, and also to examine his memory more specifically. For example the Wechslser Adult
Intelligence Scale – III (WAIS – III, Wechsler, 1998) was administered, and the results suggested that working memory and speed of information processing were impaired. The Rivermead Behavioural Memory Test (RBMT, Wilson, Cockburn & Baddeley, 1985) was also administered to find out how Mr Jones performed on typical ‘everyday’ tasks involving memory, and the Wechsler Memory Scale – III (WMS – III, Wechsler, 1998) was administered to find out whether the modality of presentation of material affected memory performance. The overall picture that emerged from Mr Jones’ performance on these tests was that Mr Jones had an impairment in visual memory and that this was likely to be due to not devoting sufficient attention to the to-be-remembered material when it was presented in the visual modality.

In the reformulation, the hypothesised memory impairment believed to underlie Mr Jones’ inability to locate his personal items was specified in more detail as a failure to attend to the available visual information when putting something away.

Outcome

The Trainee’s supervisor agreed to continue to see the client after the Trainee had finished her placement. In the light of the findings of the extended assessment, the Trainee was able to suggest a number of intervention techniques. For example, cognitive rehabilitation aimed at helping Mr Jones to develop strategies to compensate for his weaknesses in relation to visual information such as colour coding locations in the room and relying on his relative strength for processing of auditory information to help him locate his possessions. In addition, a CBT approach was proposed to help Mr Jones to manage his anger more effectively, as CBT is an effective way of helping people with LD to express feelings of anger in acceptable ways (Howells, 2000; Rose, West & Clifford, 2000). A final component of the intervention was to encourage staff to modify their style of interaction with Mr Jones, so that they no longer contributed to the maintenance of his anxiety and aggressive outbursts.
References


Child and Family Case Report Summary

Systemic (Narrative) Assessment and Intervention with a Ten-year-old Boy with Primary Nocturnal Enuresis

Presenting Problem

Fred, a ten-year-old boy of white-British origin, was referred to CAMHS by a Paediatrician because of his night-time bedwetting, for which no organic cause could be found. Fred’s mother was concerned about some of his other behaviours, therefore he was referred to CAMHS for an assessment.

Assessment

The assessment was based on interviews with Fred and his mother Lynne, and telephone conversations with Fred’s school teacher and the Special Educational Needs Co-ordinator at his school. As part of the assessment a number of psychometric measures were either administered directly to Fred or completed by his mother. These included the Self-Esteem Inventory (SEI -- Coopersmith, 1981), which Fred completed. The results of this suggested that Fred did not have particularly low self-esteem. Other measures included the Strengths and Difficulties Questionnaire (SDQ -- Goodman, 1997) and the Child Behaviour Checklist/4-18 (CBCL/4-18, Achenbach, 1991), both of which are completed by the child’s parent or guardian. Both measures revealed ‘abnormal’ scores. For example, on the SDQ, Fred obtained a “Total Difficulties” score of 22 which is in the “Abnormal” range, and on the CBCL/4-18 his “Syndrome Scale” scores were in the “Clinical” range for “Social Problems”, “Thought Problems” and “Attention Problems”. Diary sheets were used to establish the frequency of bedwetting, and revealed that Fred would not discover that he had wet the bed until waking in the morning.

Formulation

Fred’s bedwetting was formulated in terms of biological and systemic (family) factors. With regard to biological predisposing factors, the assessment revealed that other male members of Fred’s family had also suffered from this problem, and there is strong
evidence to suggest that bedwetting is hereditary (e.g. Shaffer, 1994). Another biological predisposing factor was Fred’s tendency to sleep deeply, which could mean that he was failing to wake from sleep in response to signals from his bladder (Butler & Holland, 2000).

With regard to systemic factors, there was disruption within the family environment at around the time that Fred was toilet trained – the family moved twice during the first two years of Fred’s life. Stressful life events could predispose a child to develop enuresis (Carr, 1999).

During our initial sessions Lynne would talk about Fred very negatively. One hypothesis was that Fred’s enuresis and other factors may be acting as a convenient focus for Lynne’s anxiety. Elimination difficulties may be maintained by particular patterns of family interaction (White, 1984). The formulation showed how Lynne’s problem-focused dialogue could lead Fred to feel overwhelmed, thus contributing to his difficulties.

**Intervention**

The intervention had two main components, each focussed on different levels. One was targeted at the systemic level - to help Lynne to change her problem-focused dialogue about Fred, and to recognise him as an individual aside from his problems. A Narrative approach (e.g. White & Epston, 1990) was chosen for this work. The other focused on the biological level. The formulation had suggested that one reason for Fred’s bedwetting was his inability to wake in response to a full bladder. The most effective treatment for low arousal is the urine alarm (Houts, Berman & Abramson, 1994), so it was proposed that this would be employed.

The intervention took place over twelve sessions. A number of Narrative techniques were employed to help Lynne to develop a less problem-focused dialogue about Fred. For example White (1988) advocates the use of ‘relative influence’ questioning to map how the problem has influenced lives. This technique was used to elicit more information by asking “In what ways has bedwetting been a friend/enemy?”.
process of ‘externalisation’ allows the ‘problem’ to be viewed as existing outside of the person (White, 1988), thus freeing them and their family to tackle it together. Fred was encouraged to give bedwetting a name that would be meaningful for him. Fred was also encouraged to enlist the help of his mother in listing all his good characteristics that he could fight the ‘problem’ with. Other Narrative techniques employed included identify ‘unique outcomes’ and ‘thickening the alternative story’.

In the event, the urine alarm was not introduced. This was partly because of delays in contacting the Continence Nurse to obtain an alarm, and partly because of Fred’s reluctance to use the alarm.

**Outcome**

Pre-intervention, Fred was dry for three consecutive nights a week. Post-intervention he was dry for five consecutive nights a week. Therefore in terms of reducing the frequency of bedwetting the intervention appeared to have been successful. The intervention also appeared successful in terms of modifying Lynne’s problem focused dialogue about Fred. Lynne’s dialogue about Fred became much more positive, as she sided with him in the battle against the bedwetting.
References


Specialist Case Report Summary

*Narrative Therapy with a Forty-six year old woman with Depression*

**Presenting Problem**

Bella, a 46 year-old white-Irish lady, was referred to the Psychology Service by her Psychiatrist. Bella said she had difficulty concentrating due to self-critical thoughts. She said it felt like a “Black Cloud” was weighing her down. She was worried about what others thought of her, and felt unable to make decisions.

**Assessment**

Information for the assessment was gained through interviews with Bella and a meeting with Bella’s Psychiatrist. The Clinical Outcomes in Routine Evaluation scale (CORE, Evans *et al.* 2000) was also administered. Her score suggested that she was in a high degree of distress.

The assessment suggested that Bella was suffering from depression and social anxiety.

**Formulation**

The Narrative approach was chosen for this client. This approach places importance on the meaning given by a person to their lived experience (Cowley & Springen, 1995). Narrative therapy has been shown to be effective in reducing depressive symptoms (Altschuler, 2002; Fredman, 2002) and social anxiety (Harker, 1997).

A main aim of the first few sessions of Narrative therapy is to elicit the client’s problem-focused narrative (White & Epston, 1990). At the time of the assessment, Bella’s dominant narrative seemed to be “I valued everything about my previous self, but I don’t value anything about my current self”. A second problem narrative appeared to be “I cannot mix with people as I am too intimidated by them”
A cornerstone of the therapeutic process in Narrative therapy is the creation of alternative stories (Monk, 1997). This process acknowledges human growth and consequent opportunities for the creation of alternatives to the problem story (Etchison & Kleist, 2002). Alternative stories are built upon exceptions, or times when the person has resisted the problem story. During our initial sessions Bella produced a number of exceptions to her dominant narratives.

Narrative therapy assumes that the wider social, cultural and political contexts play a role in shaping and maintaining problems (White & Epston, 1990). On an intra-individual level, problems are maintained when the person sees the problem as residing within them, and creates stories about him/herself that are consistent with the problem. Therefore possible alternatives remain unstoried (Etchison & Kleist, 2002). Bella preferentially attended to information that provided evidence for the dominant narrative, thereby maintaining it.

**Intervention**

The initial formulation indicated that a number of Narrative techniques could be fruitfully applied. For example questions that map the influence of the problem on the person, and of the person on the problem, can help the therapist and client to see the problem as distinct from the client and their life, thus contributing to the externalisation of the problem (Monk, 1997). Therefore I asked Bella questions to find out in what ways the Black Cloud affected her daily life, and in what ways she influenced the Black Cloud.

The development of alternatives to the dominant problem narrative is contingent upon the therapist and client identifying exceptions – times when the client has been able to resist the problem. During our externalising conversations I helped Bella to identify ‘exceptions’ and encouraged curiosity about what was different about those times.

Deconstruction is the process by which the taken-for-granted assumptions that reside within and maintain the dominant narrative are pulled apart and examined, in order to locate the social context from which they have originated (Harker, 1997). I aimed to
help Bella deconstruct ideas around being intimidated by others. We completed a
genogram to tease apart the assumptions that appeared to maintain the dominant
narrative, and locate them within the social context from which they might have
originated.

**Outcome**

Bella chose to terminate therapy prematurely. This followed a resurgence of her
difficulties associated with weight-gain. Although Bella’s global CORE score fell
within the non-clinical range mid-therapy, just prior to her terminating therapy it was
back in the clinical range. Once the beginnings of an alternative story are highlighted,
it must be made more substantial (Freedman & Coombs, 1996). One way to do this is
to write the person a therapeutic letter to serve as a written document, evidencing the
alternative story (White & Epston, 1990). Therefore Bella was sent a therapeutic
letter to mark the end of therapy and to document our progress.
References


Older People Case Report Summary

*Extended Assessment of a Seventy-five year-old man with a right hemisphere stroke injury*

**Presenting Problem**

Bob, a 75-year-old white-British man, was referred by his GP after the GP had received a referral from the Occupational Therapist (OT). The OT had treated Bob following his right middle cerebral artery infarct. The OT observed that Bob was poorly motivated, and requested a detailed assessment of Bob’s cognitive abilities.

**Assessment**

Bob was seen twice for a general assessment using a holistic semi-structured interview. This provided the necessary contextual information to allow interpretation of the results of any cognitive tests. During the initial assessment Bob often looked out of the window whilst answering questions, and was slow to respond. He appeared to be easily distracted. He would often make jokes and start to laugh, but his face would then crumple as if he were on the verge of tears. He usually seemed unaware of this expression and it was extremely transient.

Bob’s wife was also seen as part of the assessment process. She was seen individually as it seemed important to gain both her’s and Bob’s perspectives.

Bob’s consent was explicitly sought both at the start of the assessment process and at frequent intervals during the assessment.

**Formulation**

The formulation took the form of a series of aims and hypotheses, developed as a result of a review of the literature regarding the consequences of right middle cerebral artery infarcts. The first aim was to use appropriate psychometric tests to identify Bob’s cognitive strengths and weaknesses. Based on the literature it was predicted
that Bob would show deficits in visuospatial abilities, memory and executive functions.

Another aim was to assess Bob's affective status using appropriate measures, and to use this information, together with qualitative observations, to help discover whether a) Bob's lack of motivation and distractibility were due to i) depression or ii) organic brain damage; b) Bob's tearful expression was due to i) depression or ii) a stereotypic response driven by damaged neurological mechanisms.

**Intervention**

As this was an extended assessment, the 'intervention' phase took the form of administering a number of psychometric measures. These included the Wechsler Test of Adult Reading (WTAR, Wechsler, 2001) to estimate Bob's premorbid intellectual functioning, the Wechsler Adult Intelligence Scale (WAIS – III, Wechsler, 1999) to gain information about Bob's current general intellectual functioning and specific cognitive strengths and weaknesses, the Rivermead Behavioural Memory Test (RBMT, Wilson, Cockburn & Baddeley, 1991) to look at Bob's performance on 'everyday' memory tasks, and various tests of executive functioning (e.g. the Verbal Fluency Test from the Delis-Kaplan Executive Function System (D-KEFS, Delis, Kaplan & Kramer, 2001). Bob's affective status was assessed using the Hospital Anxiety and Depression Scale (HADS, Zigmond & Snaith, 1983) and the Geriatric Depression Scale (Yesavage et al. 1983).

The first prediction, that Bob would show deficits in visuospatial abilities, memory and executive functions, was supported. In general, his performance was relatively poorer on the Performance subtests of the WAIS-III than on the Verbal subtests. Although some of this poor performance could be attributed to slowed processing speed, visuo-spatial impairment appeared to contribute to poor performance on other activities such as Block Design and Picture Arrangement subtests of the WAIS-III and the route recall subtest of the RBMT.
With regard to the question of the origin of Bob’s lack of motivation and distractibility, his scores on the measures of affect, coupled with his humorous comments and matter-of-fact attitude towards the difficulties highlighted during testing suggested that he was not clinically depressed. Such characteristics have been specifically related to right hemisphere brain damage (Aszalos, Barsi, Vitrai & Nagy, 2002).

Bob’s tearful expression was perhaps more likely to reflect a stereotypical, automatic response caused by damage to the neurological mechanisms controlling facial expression, rather than depressed mood. The literature review suggested that this damage could have occurred in the right hemisphere, in the corticobulbar motor pathways, or in the orbitofrontal cortex (or a combination).

Outcome

Bob and his wife were given practical advice to help them to predict what everyday tasks Bob would be likely to find difficult, based on the results of the assessment. They were also give advice around how Bob could help himself to stay motivated. Bob’s distractibility, lack of motivation and laid back attitude were framed in terms of the location of stroke damage.
References


Summary of Research Dossier

The Service Related Research Project, the Major Research Project, and the Research Logbook are contained within this section. The work is intended to represent the depth and variety of research skills acquired over the three years. As with previous sections, the work is presented in the order that it was completed, to demonstrate the development of skills over the course of training.
Identification of outcome categories for a primary care service

Service Related Research Project

June 2003

Year One
ABSTRACT

A primary care service used a database to record client details, but clients were categorised according to only two outcomes. The study aimed to identify more informative outcome categories using archived information about clients seen between 1998 and 2002. It also aimed to look at the relationship, first, between waiting time and attendance at initial appointment, and second, between severity of depression at outset of therapy and premature termination of treatment. Nine outcome categories were identified. Non-parametric analyses failed to reveal a significance difference between the waiting times of those that attended and did not attend their initial appointment, although the difference was in the predicted direction. Neither was there a significant difference between severity of depression at outset of therapy and premature termination. A main limitation of the study was the lack of statistical power due to small sample sizes. Future research might aim to develop a questionnaire to send to clients soon after referral, since such a procedure may reduce the likelihood of non-attendance at initial appointments (Foreman & Hanna, 2000).
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INTRODUCTION

Clinical governance
Clinical governance is a process aimed at continuous improvement of service quality and the maintenance of high standards within NHS organisations (Department of Health website: http://www.doh.gov.uk/pricare/clingov.htm). Bloor & Maynard (1998) suggest one activity that can enable service improvement: the use of high quality systems of record keeping. Clearly, improvement of service quality is dependent upon accurate knowledge of the standards currently being achieved. These standards can only be evaluated if the service has recorded accurate information about outcomes for its' users.

The service
The primary care service upon which this investigation is based receives referrals from GPs regarding clients with a variety of psychological difficulties. Following referral clients are placed on a waiting list, and are seen by the Clinical Psychologist (or sometimes by a counselling psychologist or trainee) usually at their local GP surgery.

Recording of outcome
A database was set up by the service in 1995, to meet government requirements for service evaluation. The database enables demographic information and outcome measures such as the Hospital Anxiety and Depression Scale (HADS, Zigmond & Snaith, 1983) to be recorded. At the time of this research, clients were categorised into one of two groups according to their scores on the various outcome measures: “treatment” if the client was successfully treated, or “assessment” if otherwise. A previous trainee found that the database did not contain specific information about why those classified as “assessment” had not completed treatment. There is a need to discover why these clients did not complete therapy, and to use this information to generate new outcome categories. More specific information about outcome should contribute to the service’s understanding of standards currently being achieved, allowing for accurate monitoring and improvement of service quality.
A search of archived data should enable the identification of specific outcome categories, for example “failed to attend initial appointment” and “dropped-out of therapy prematurely”.

Failure to attend an initial appointment
This represents a problem for clinical psychology services (e.g. Stern & Brown, 1994) and leads to significant wastage of NHS resources (Loumidis & Shropshire, 1997). It is likely that a proportion of those currently classified as “assessment” failed to attend their initial appointment. Time spent on a waiting list has been related to attendance at initial appointment. In a child and adolescent service, families required to wait more than 30 weeks tended to ‘give up’ on the idea of therapy (Foreman & Hanna, 2000). In an outpatient clinical psychology service, patients who didn’t attend their initial appointment had to wait for a further six weeks on average than those who did attend (Loumidis & Shropshire, 1997). Finally couples referred for relationship counselling were significantly less likely to attend their initial appointment if it was four or more weeks post-referral (Hicks & Hickman, 1994). Therefore with regard to the current service, those who failed to attend their first appointment may have had to wait significantly longer for an appointment than those who did attend.

The government has centred attention on the issue of waiting times (e.g. Patient’s Charter, 1991, cited in Hicks & Hickman, 1994), and so there is increasing demand for psychologists to use forms of short-term therapy with established effectiveness. Cognitive-behaviour therapy (CBT) is often the treatment of choice because it is time-limited and has much evidence to support its effectiveness for a variety of disorders including panic disorder (Clark et al. 1994), social phobia (Clark & Wells, 1995, cited in Clark, 1997), and bulimia nervosa (Wilson & Fairburn, 1998). This form of therapy requires collaboration between therapist and client, and ‘homework’ tasks are deemed fundamental to treatment (Beck, Rush, Shaw & Emery, 1979, cited in Edelman & Chambless, 1995).
**Premature termination of therapy**

CBT is the dominant treatment model employed in the current service. During her placement, the trainee observed that a number of her clients terminated therapy prematurely, apparently because of their unwillingness/inability to complete homework tasks. This tendency for some clients to ‘drop-out’ of therapy prematurely has been reported elsewhere in the literature (and is not specific to CBT). Oei & Kazmierczak (1997) found that 62/131 clients involved in cognitive-behavioural group therapy for depression dropped-out before completing treatment. Keijsers, Kampman & Hoogduin (2001) found that 32/161 clients with panic disorder dropped-out of CBT treatment prematurely. Reasons included lack of motivation (50%) and practical/private reasons (17.6%). Thus a proportion of clients in the current service categorised as “assessment” may have prematurely terminated therapy.

Furthermore, some studies have found that higher levels of depression at the start of therapy are predictive of premature termination. This relationship has been identified in depressed clients (Persons, Burns & Perloff, 1988), agoraphobic clients (Burke, Drummond & Johnston, 1997) and clients with bulimia nervosa (Steel *et al.* 2000). It is plausible that clients identified in this study as “premature terminators” will be characterised by significantly higher scores on the HADS depression subscale than clients who successfully completed treatment.

**AIMS/PREDICTIONS**

**Aim:** to identify specific outcome categories for those clients referred to the service between 1998 and 2002 whom have been discharged and are currently recorded in the database as “assessment”.

**Predictions:**

1. a) A proportion of clients currently categorised as “assessment” will have failed to attend their initial appointment.
   b) The mean number of days spent on the waiting list will be significantly higher for these clients than for a group of clients randomly sampled from those who did attend their first appointment.
2. a) A proportion of clients currently categorised under “assessment” will have dropped-out of therapy prematurely.
b) The mean score on the HADS depression subscale will be significantly higher for these clients than for those who successfully completed treatment.

METHOD

Sample
The database was used to generate a list of all clients referred to the primary care psychology service between 1998 and 2002. Ninety-one clients were sampled in total, 54 classified in the database as “assessment” and 37 classified as “treatment”.

Measures
The Hospital Anxiety and Depression Scale (HADS, Zigmond & Snaith, 1983) is administered routinely at the outset and end of therapy. The HADS contains two likert-type self-report scales (seven items each), measuring depression and anxiety. A score of 8-10 points or more on either subscale is indicative of clinical disorder. The HADS has high concurrent validity (Zigmond & Snaith, 1983) and high internal consistency (Moorey et al. 1991).

Procedure
Having identified the sample (see above) precise date of discharge were identified using an existing filing system of index cards, enabling the archived files to be located. It was hoped that all assessment and a random sample of treatment cases (for comparison purposes) would be sampled. However several cases could not initially be traced, and in the event there was not sufficient time to conduct further searches. The client’s age, sex, the referring problem, date of referral, who saw the client, date of first appointment, initial HADS scores, and the outcome were extracted from each of the 91 files located. Individual outcomes were then regrouped according to new categories (see below).
RESULTS

Identification of outcome categories
Table 1 shows each new outcome category, the number of clients within it, number of males and females, mean age, and referral problem. Anxiety disorders included phobias, panic attacks and generalised anxiety. Where a category has more than four members, only the most common classes of referral problem are reported, and all single incidences of a problem are classed as “other”. Full listings of referral problems in each category are given in Appendix 1. Although 37 “treatment” cases were initially identified, only 22 of these were actually successfully treated, with the remainder falling into one of the other outcome categories given in Table 1. Discussion with the clinical psychologist revealed that “treatment” was the default option on the database, and time pressure had meant that a number of clients who failed to complete therapy had not yet had their outcome changed to “assessment”.

All statistical analyses described in the remainder of the results section were non-parametric because scores on dependent variables were not normally distributed. All analyses were two-tailed.

Prediction 1
Table 1 shows that 17 of the 91 clients sampled did not attend their first appointment, thus prediction 1 a) is supported. It was also predicted that the mean number of days spent on the waiting list would be significantly higher for clients who did not attend their initial appointment than for a group of clients randomly sampled from those who did attend their first appointment (prediction 1 b). Table 2 shows the number of males and females, mean ages, referral problems and mean waiting times of those who failed to attend their first appointment (non-attenders) and a random sample of those who attended their first appointment (attenders). All clients in the “non-attender” group and all but one in the “attender” group were offered an appointment with the clinical psychologist (the remaining client was seen by a trainee).
<table>
<thead>
<tr>
<th>Category</th>
<th>Referring Problem</th>
<th>m Age (sd)</th>
<th>P</th>
<th>F</th>
<th>M</th>
<th>No.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other</td>
<td>Other</td>
<td>34.83 (15.92)</td>
<td>6</td>
<td>3</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Alcohol addiction</td>
<td>Alcohol addiction</td>
<td>2.00 (2.49)</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>Depression</td>
<td>26.50 (2.12)</td>
<td>2</td>
<td>0</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Anger</td>
<td>Anger</td>
<td>33.50 (12.79)</td>
<td>4</td>
<td>2</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>Other</td>
<td>33.75 (15.69)</td>
<td>4</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>PTSD</td>
<td>40.44 (20.02)</td>
<td>6</td>
<td>3</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td>Anxiety</td>
<td>3.18 (10.50)</td>
<td>11</td>
<td>7</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>Other</td>
<td>32.50 (13.74)</td>
<td>16</td>
<td>6</td>
<td>9</td>
<td>25</td>
</tr>
<tr>
<td>Anger</td>
<td>Anger</td>
<td>37.80 (14.84)</td>
<td>16</td>
<td>9</td>
<td>25</td>
<td></td>
</tr>
</tbody>
</table>

*Note: The number of referrals for each category was calculated by multiplying the number of referrals for each category by the number of clients falling into each category. The table shows the number of referrals for each category, along with the mean age and number of referrals for each category.*
Table 2: Demographic details, referral problems and mean no. of days on waiting list for attenders and non-attenders.

<table>
<thead>
<tr>
<th>Group</th>
<th>N</th>
<th>M</th>
<th>F</th>
<th>m Age (sd)</th>
<th>Referral problem</th>
<th>m Wait in days (sd)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attenders</td>
<td>17</td>
<td>10</td>
<td>7</td>
<td>43.53 (17.26)</td>
<td>Anxiety (4)</td>
<td>155.53 (114.09)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>PTSD (4)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Depression (3)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Anx. &amp; Dep. (2)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Other (4)</td>
<td></td>
</tr>
<tr>
<td>Non-Attenders</td>
<td>17</td>
<td>7</td>
<td>10</td>
<td>33.18 (10.50)</td>
<td>Anxiety (10)</td>
<td>208.94 (76.27)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Depression (2)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Other (5)</td>
<td></td>
</tr>
</tbody>
</table>

A Mann-Whitney $U$ test was used to compare the mean waiting time between the groups. Although in the expected direction, the results were non-significant, $z = -.150$, $p > .05$.

Prediction 2
Table 1 shows that 25 of the 91 clients sampled dropped out of therapy prematurely. Therefore prediction 2 a) has been supported.

It was also predicted that the mean score on the HADS depression subscale would be significantly higher in those who have dropped-out compared to those who successfully completed treatment. Prior to conducting any analyses, any clients seen by a trainee or counsellor rather than a qualified clinical psychologist were excluded as this may have affected likelihood of clients completing treatment. This resulted in the exclusion of one client from each group. In addition clients with missing HADS depression scores were also removed, resulting in the exclusion of a further two clients from each group. Table 3 shows the number of males and females, mean ages, referral problems and mean HADS depression subscale scores for those who
successfully completed treatment (completers) and those who dropped-out of therapy prematurely (non-completers).

Table 3: Demographic details, referral problems and mean HADS depression subscale scores for completers and non-completers.

<table>
<thead>
<tr>
<th>Group</th>
<th>N</th>
<th>M</th>
<th>F</th>
<th>m Age (sd)</th>
<th>Referral problem</th>
<th>m HADS depression score (sd)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Completers</td>
<td>19</td>
<td>6</td>
<td>13</td>
<td>35.47 (11.45)</td>
<td>Anxiety (10)</td>
<td>6.84 (4.31)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Eating dis. (2)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Other (8)</td>
<td></td>
</tr>
<tr>
<td>Non-Completers</td>
<td>22</td>
<td>8</td>
<td>14</td>
<td>37.73 (15.61)</td>
<td>Anxiety (9)</td>
<td>6.73 (2.81)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Depression (4)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Anx. &amp; Dep. (3)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Anger (2)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Other (4)</td>
<td></td>
</tr>
</tbody>
</table>

Table 3 shows that there is very little difference between the HADS depression subscale scores for each group. A Mann-Whitney $U$ test was used to confirm that there was no significant difference between the two scores, $z = -.290$, $p > .05$.

DISCUSSION

Identification of outcome categories

Nine new outcome categories were generated based on information available in archived files. As predicted, a proportion of clients previously classified as “assessment” had not attended their first appointment. This is consistent with the findings of other services (e.g. Stern & Brown, 1994). It is possible that some clients
may have resolved their difficulties without the help of a psychologist. Arrindell (2001) found that severity of psychiatric patients' symptoms reduced over the waiting period despite no intervention having taken place. One suggestion is that natural coping mechanisms are evoked during the wait for treatment (Sharpe & Gilbert, 1998, cited in Arrindell, 2001). This may have been the case for some clients belonging to the “non-attender” group in this study, since close inspection of their files revealed that some had cancelled their first appointment claiming they had sorted the problem out for themselves.

Also as predicted, a proportion of clients dropped out of therapy prematurely. A number of these clients appeared to have failed to ‘engage’ in therapy, by for example failing to complete homework tasks involving graded exposure. This is consistent with Keijsers et al.’s (2001) finding of lack of motivation as a reason for dropping-out of CBT, and implies a need for evidence of the client’s motivation prior to embarking on a course of therapy (through assessment of motivation for change—e.g. see Proschaska & DiClemente [1992]—during initial assessment).

**Time spent on waiting list and attendance at initial appointment**

No significant difference was found between the mean number of days spent on the waiting list for those who attended their initial appointment versus those who did not attend. However, the results provided tentative support for the prediction since they were in the expected direction, with “attenders” spending an average of 156 days on the waiting list compared to “non-attenders” who spent an average of 209 days. This difference is consistent with the findings of previous studies (e.g. Foreman & Hanna, 2000). The relationship between waiting time and attendance at the first appointment is perhaps complicated by other factors that this study did not have the scope to explore, including socio-economic status, (Lefebvre et al. 1983, cited in Stern & Brown, 1994) and prior contact with the service (Loumidis & Shropshire, 1997).

**HADS depression score at outset of therapy and premature termination of therapy**

The mean HADS depression score of clients who terminated therapy prematurely was virtually the same as that of clients who successfully completed therapy. Thus the
prediction was not supported. Previous studies that have identified a relationship between severity of depressive symptoms at the start of therapy and premature termination have focused on clients sharing the same diagnosis (e.g. Burke et al. 1997; Steel et al. 2000). Those identified as having prematurely terminated therapy in this study had a wide range of disorders at referral, including anxiety disorders, relationship difficulties and self-harm. The heterogeneity of this group may thus have masked any relationship between depressive symptoms at the outset of therapy and premature termination.

Limitations of this study
The main limitation was the small sample sizes of the different outcome categories. Larger samples may have meant that groups were more normally distributed with regard to the dependent variables, thus allowing the use of more powerful parametric tests. Post-hoc power analyses revealed that the power of the study was low (see Appendix 2). A practical limitation of using information from a database that was set up relatively recently in a fairly small service (one full-time clinical psychologist working in the adult mental health setting) is that the number of clients seen is relatively low compared to services employing more psychologists. Had more data been collected, sizes of groups may have become increasingly unequal, thus violating the assumption of homogeneity of variance. Therefore the database will take time to build up to a size sufficient to allow the use of parametric analyses.

Recommendations to the service and future research
This study highlighted several outcome categories in a sample of clients previously categorised in the database under "assessment". It is proposed that the nine new categories replace the existing categories of "assessment" and "treatment" in the database, as they are more informative. The service can record future cases according to these new categories, and use the information to monitor current standards and improve them, thus going someway to fulfilling the requirements of clinical governance.

One way in which the service could seek to cut-down both the number of non-attenders to initial appointments and premature terminators of therapy might be to
introduce a system whereby patients are seen for a session immediately after referral and then placed on a waiting list. Westbrook (1995) reported high rates of client satisfaction with such a procedure, and Shawe-Taylor, Richards, Sage & Young (1994) reported increased coping and optimism ratings in clients immediately after early assessment. There is evidence to suggest that early contact, even in the form of a questionnaire (Foreman & Hanna, 2000) increases the probability of attendance at initial appointments. Loumidis & Shropshire (1997) highlighted the importance of considering the attitudes and beliefs of waiting list clients regarding therapy. An early assessment session would enable such attitudes and beliefs to be exposed, and would allow the collaborative nature of therapy to be discussed. Such a procedure may reduce the number of clients who drop out of therapy prematurely as well as increasing appointment attendance. However the routine offering of assessment sessions immediately post-referral is likely to be costly in terms of the psychologist’s time. Thus a questionnaire sent out soon after referral may be a viable alternative, and the design of such a questionnaire could be the focus of future service related research.
References


Appendix 1

Full listing of referral problems per outcome category as listed in Table 1.
Client dropped out of therapy prematurely

<table>
<thead>
<tr>
<th>Problem</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>anger</td>
<td>2</td>
</tr>
<tr>
<td>anx&amp;dep</td>
<td>3</td>
</tr>
<tr>
<td>anxiety</td>
<td>9</td>
</tr>
<tr>
<td>depress</td>
<td>6</td>
</tr>
<tr>
<td>lowselfe</td>
<td>1</td>
</tr>
<tr>
<td>moodswi</td>
<td>1</td>
</tr>
<tr>
<td>ptsd</td>
<td>1</td>
</tr>
<tr>
<td>relatdif</td>
<td>1</td>
</tr>
<tr>
<td>selfharm</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>25</strong></td>
</tr>
</tbody>
</table>

Client successfully completed treatment

<table>
<thead>
<tr>
<th>Problem</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>alcoadic</td>
<td>1</td>
</tr>
<tr>
<td>anger</td>
<td>1</td>
</tr>
<tr>
<td>anxiety</td>
<td>12</td>
</tr>
<tr>
<td>bodyima</td>
<td>1</td>
</tr>
<tr>
<td>dep&amp;sib</td>
<td>1</td>
</tr>
<tr>
<td>depress</td>
<td>1</td>
</tr>
<tr>
<td>eatdis</td>
<td>2</td>
</tr>
<tr>
<td>lowselfe</td>
<td>1</td>
</tr>
<tr>
<td>ptsd</td>
<td>1</td>
</tr>
<tr>
<td>relatdif</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>22</strong></td>
</tr>
</tbody>
</table>

Client did not attend first appointment

<table>
<thead>
<tr>
<th>Problem</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>anger</td>
<td>1</td>
</tr>
<tr>
<td>anxiety</td>
<td>10</td>
</tr>
<tr>
<td>bereave</td>
<td>1</td>
</tr>
<tr>
<td>cogasse</td>
<td>1</td>
</tr>
<tr>
<td>depress</td>
<td>2</td>
</tr>
<tr>
<td>eatdis</td>
<td>1</td>
</tr>
<tr>
<td>lowselfe</td>
<td>1</td>
</tr>
</tbody>
</table>
Total 17

Client unsuitable for treatment in primary care

<table>
<thead>
<tr>
<th>Problem</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>anger</td>
<td>1</td>
</tr>
<tr>
<td>anxiety</td>
<td>3</td>
</tr>
<tr>
<td>depress</td>
<td>1</td>
</tr>
<tr>
<td>ptsd</td>
<td>3</td>
</tr>
<tr>
<td>relatdif</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>9</td>
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</tbody>
</table>

Client asked to be removed from waiting list

<table>
<thead>
<tr>
<th>Problem</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>anxiety</td>
<td>1</td>
</tr>
<tr>
<td>psychos</td>
<td>3</td>
</tr>
<tr>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>4</td>
</tr>
</tbody>
</table>

Client on waiting list for at least nine months & did not reply to letter asking if appointment still needed

<table>
<thead>
<tr>
<th>Problem</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>anger</td>
<td>1</td>
</tr>
<tr>
<td>anxiety</td>
<td>1</td>
</tr>
<tr>
<td>gambling</td>
<td>1</td>
</tr>
<tr>
<td>sleep di</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>4</td>
</tr>
</tbody>
</table>
Client completed treatment but did not engage in therapy/make desired changes

<table>
<thead>
<tr>
<th>Problem</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>anxiety</td>
<td>1</td>
</tr>
<tr>
<td>depress</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>2</td>
</tr>
</tbody>
</table>

Client could not be contacted to arrange appointment

<table>
<thead>
<tr>
<th>Problem</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>anxiety</td>
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<tr>
<td>drugadic</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>2</td>
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</table>

Other

<table>
<thead>
<tr>
<th>Problem</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
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<td>anger</td>
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</tr>
<tr>
<td>cogdeter</td>
<td>1</td>
</tr>
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<td>depress</td>
<td>1</td>
</tr>
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<td>ptsd</td>
<td>1</td>
</tr>
<tr>
<td>relatdif</td>
<td>2</td>
</tr>
<tr>
<td>Total</td>
<td>6</td>
</tr>
</tbody>
</table>
Appendix 2

Power Calculations
Prediction 1:
Mean waiting time will be significantly higher for those who did not attend their first appointment compared to a random sample of those who did attend their first appointment.

t-test for means, post hoc analysis, accuracy mode:
Effect size d = 0.5, Alpha = 0.05, sample sizes: n1 = 17, n2 = 17, two-tailed. Power = 0.2930; critical t (32) = 2.0369; Delta = 1.4577.

Prediction 2:
Mean HADS depression subscale score will be significantly higher for those who dropped-out of therapy prematurely compared to those who successfully completed therapy.

t-test for means, post hoc analysis, accuracy mode:
Effect size d = 0.5, Alpha = 0.05, sample sizes: n1 = 19, n2 = 22, two-tailed. Power = 0.3438, critical t (39) = 2.0227, Delta = 1.5965.
Appendix 3

Audit Declaration Form
University of Surrey

PSYCHD CLINICAL PSYCHOLOGY

Service Related Research Project

Ethical Scrutiny Form

The nature of the proposed project is such that I am satisfied that it will not require scrutiny by the trust's ethical committee.

Name of Supervisor:...........................................

Signature of Supervisor:....................................

Name of Trainee: HAYLEY PRIEGE

Title of SRRP: IDENTIFICATION OF TYPES OF OUTCOME AND RELATIONSHIPS BETWEEN OUTCOME AND SPECIFIC FACTORS SUCH AS WAITING TIME FOR USERS OF A PRIMARY CARE SERVICE BETWEEN 1997 - 2002

Date: 13/12/02
Appendix 4

Cover letter that will be sent to service, together with copy of the SRRP project
10th June, 2003

Dear Mike

Re: Service Related Research: "Identification of outcome categories in a primary care service"

Thank you for the advice that you gave me with regard to the above project. I have now completed the project and have enclosed a copy with this letter.

As you will see, a search of the archived files of discharged clients revealed a number of outcomes, including "dropped-out of therapy prematurely" (n=25) and "failed to attend initial appointment" (n=17).

Based on existing evidence, it was predicted that those who had not attended their initial appointment would have a mean length of waiting time significantly longer than a random sample of those who did attend their first appointment. No significant difference was found, although the difference in mean waiting times was in the expected direction.

It was also predicted that those who dropped-out of therapy would have a mean HADS depression subscale score significantly higher than those who successfully completed treatment. Again, no significant difference was found. Indeed, the HADS depression subscale scores of the two groups were almost the same.

A main limitation of this study was the small sample size, which resulted in a lack of statistical power. However, the study revealed some useful findings. It is recommended that the new outcome categories identified in this project are built into the database to enable more accurate monitoring of outcome. In addition, given the finding of increased waiting times in those who failed to attend their initial appointment, you may wish to consider seeing clients for assessment immediately after referral and before being placed on a waiting list, or sending a questionnaire to find out about clients' attitudes and beliefs prior to an appointment being offered. Both of these methods have been shown to reduce non-attendance at initial appointments.

If you would like for me to return to the service to discuss any of the issues raised in the project, or perhaps formally present the research findings to yourself and/or your colleagues, please feel free to contact me.

Yours sincerely,

Hayley Pringle
Trainee Clinical Psychologist
Appendix 5

Email from AMH Placement Supervisor Acknowledging receipt of feedback of SRRP findings
Dear Hayley

Thank you very much for sending me your SRRP. Your work was a helpful part in the redesign of a database structure to separate out the categories of incomplete treatments. My copy did not include Table 1 (please send) which I would like to have examined because you have surprisingly low figures for completed treatments. However, I don't think this would have had a bearing on your findings.

Yours

Mike Tossell
CARERS' EXPERIENCES OF CHALLENGING BEHAVIOURS IN PEOPLE WITH LEARNING DISABILITIES: AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS OF PROFESSIONAL CARER'S UNDERSTANDING OF SPECIFIC INCIDENTS OF CHALLENGING BEHAVIOUR

Major Research Project
July 2005
Year 3
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ABSTRACT


Main Aim: To discover more about how care staff experience and understand the challenging behaviours (CB) of the people with learning disabilities who are in their care.

Design & Analysis: A retrospective design was employed, eliciting carers' accounts by means of a semi-structured interview. Interview transcripts were then subjected to Interpretative Phenomenological Analysis.

Participants: Ten participants were interviewed in all (six men and four women). All were paid carers working in residential homes in the community for people with learning disabilities.

Outcome: Three superordinates themes emerged from the analysis, labelled Understanding of CB, Attempting to Intervene and Sources of Knowledge and Support. Participants' conceptualisations of CB varied in terms of how much they resembled definitions available in the published literature. Participants' causal explanations also varied in terms of the range of contributory factors considered. Participants whose causal explanations were more restricted also tended to hold the client responsible for their actions and to feel anger toward the client. Participants spoke of attempts to conceal or deny their feelings. Exhaustion was linked to failing to identify triggers (so that early intervention was not possible), and a desperate attempt to try to make sense of the incident of CB. In attempting to intervene, participants spoke of the immediate need to assess risk and to act accordingly. Informal support from colleagues was identified as important in helping care staff to cope with the CB, as was direct experience with the clients themselves.
**Clinical Implications:** The findings highlight a number of factors that could potentially contribute to stress in care staff. Of particular interest was the finding of how failure to identify triggers can lead to desperate attempts to make sense of the incident and consequent exhaustion. In the light of this finding, external consultants responsible for designing interventions and teaching Positive Behavioural Support (PBS) principles are encouraged to review the suitability of messages suggesting that triggers to challenging behaviour are *always* present and identifiable.
INTRODUCTION

Learning Disabilities and Challenging Behaviour

World wide, as many as three in every one hundred people have a learning disability (LD) (World Heath Report, 2001). In the UK, 230,000 – 350,000 have a severe learning disability, and 580,000 – 1,750,000 have a mild learning disability (The Foundation for People with Learning Disabilities, 2001).

Challenging behaviours (CB) are reportedly exhibited by between 10% and 15% of people with learning disabilities (Emerson et al. 2001). CB can be defined as any culturally abnormal behaviour, which, by virtue of its duration, intensity or frequency, poses a serious threat to the physical safety of the person or others, or is likely to seriously restrict their access to community facilities (Emerson, 1995). Examples of CB include physical aggression to other people or to aspects of the environment (furniture, windows etc) and self-injurious behaviours.

CB can result in the exclusion, neglect and abuse of the individuals concerned (see Allen, James, Evans, Hawkins & Jenkins, 2005). Therefore there is a need for research in this area to look at how we can attempt to reduce or eliminate such behaviours in this population.

The Current Dominant Model of Intervention for Challenging Behaviours — ‘Positive Behavioural Support’

A number of different theories or explanations of CB have been proposed, including neurobiological factors (e.g. Aman, Arnold & Armstrong, 1999, but see Emerson 2001 chapt. 4 for an overview) and attachment difficulties (Janssen, Shuengel & Stolk, 2002; Clegg & Sheard, 2002). Each theory suggests different approaches to intervention. However, the current dominant model of intervention for CB shown by people with learning disabilities is an approach that has come to be called ‘Positive Behavioural Support’, or PBS (Horner, Dunlap & Koegel, 1990 but see Allen, James, Evans, Hawkins & Jenkins, 2005 for a review). It is the approach advocated in the British Psychological Society’s Clinical Practice Guidelines (Ball, Bush & Emerson,
Furthermore, its evidence base for use with people with learning disabilities is better established than that of other approaches, such as Cognitive Behavioural Therapy and Psychotherapy (Frankish & Terry, 2003).

Interventions based on behavioural principles have long been considered to be the most effective form of intervention to reduce the incidence of CB in people with learning disabilities. However over the years these interventions have undergone gradual changes, which have broadly paralleled developments in human rights awareness. These changes included the widespread rejection, in the late '80s and early '90s, of interventions based on aversive stimuli, on the grounds that they were ethically unacceptable. Examples of aversive stimuli used during the 1980s included forced body movement, noxious chemicals placed under the nose and electric shocks (Scotti, Evans, Meyer & Walker, 1991). Unlike its predecessors, PBS is widely regarded as ethically and morally acceptable. PBS can be viewed as the product of an assimilation of two elements. First, applied behavioural analysis, which is concerned with an examination of the environmental factors that shape the behaviours of the individuals within those environments. Second, social role valorisation, which advocates that within every community people with learning disabilities should be able to hold socially valued roles (Wolfensberger, 1972).

Allen et al. (2005) outline a number of essential characteristics that help to distinguish PBS from its predecessors, and three will be outlined here.

- First, it is based on an understanding of the reasons for behaviours and their purpose, with this understanding being based on a functional analysis of the behaviours in question. PBS advocates that CB can be functional. For example, a person with a severe learning disability who cannot communicate verbally may instead act aggressively towards his carer in order to avoid a situation that he finds aversive. This behaviour then becomes functional since the carer terminates the aversive activity immediately following the aggressive act. Functional analysis is an assessment process entailing detailed observation and description of the challenging behaviour, including its form (topography), when and where it occurs, what triggers the behaviour and what appears to be maintaining it. Interventions
can then be targeted at reducing the individual’s CB and facilitating the
development of more adaptive communication skills (the interested reader is
advised to consult Emerson, 2001 Chapt 6 for further information on functional
analysis).

- Second, PBS encourages the identification of factors that act to trigger an
individual’s CB (‘triggers’). Examples of possible triggers might include the
individual with LD being thwarted in their attempts to do something, feeling
isolated, not understanding what they are being asked to do or being faced with
aggressive body language from another person. PBS advocates the subsequent
alteration of such factors in order to reduce the CB. This might entail a change in
the carer’s interpersonal approach, providing the person with the learning
disability with more choice, or reducing the demands placed on them (Allen et al.
2005).

- Third, the approach makes a clear distinction between proactive strategies aimed
at preventing the occurrence of CB (e.g. by avoiding known triggers and teaching
the person new skills) and reactive strategies aimed at managing CB when they do
occur. With regard to reactive strategies, PBS places increased emphasis on the
importance of early intervention by carers to prevent situations from escalating to
a point where CB does occur.

Despite its obvious strengths, the PBS approach is not practised as widely as might be
expected. For example, research has shown that only 2 - 20% of people CB receive
any kind of behavioural support (Oliver, Murphy & Corbett 1987; Harris & Russell,
1989; Quereshi, 1994). This is in contrast to psychotropic medication (50-60% of
people with learning disabilities and CB are estimated to be in receipt of such
medication – Fleming, Caine, Ahmed & Smith, 1996) and restraint (at least 50% of
people with LD and CB will be subjected to restraint on a regular basis, Emerson,
2002).
The Role of Care Staff

'Front-line' care staff involved in the daily care of people with LD and CB in residential settings play a crucial part in the implementation of interventions to reduce the occurrence of CB (Allen, 1999). Tharp & Wetzel, (1969) proposed a triadic model of intervention involving three levels of influence; behavioural consultants would influence the behaviour of care staff (or 'mediators'), who would then influence the behaviour of those individuals with LD and CB. Through the use of such a model, a limited number of professionals could advise on interventions to a wider number of care staff who could then be responsible for their direct implementation in the natural environment.

Suggested Reasons for Non-Usage of PBS

A number of factors have been suggested as contributing to non-usage of PBS such as lack of provision of funding and preference of services for drugs and physical restraint as interventions. However even when services do have access to professionals skilled in the design and application of behavioural techniques consistent with PBS, care staff may fail to implement interventions in the recommended way (e.g. Oliver, Hall, Hales & Head, 1996). There is a need to discover why this is so. One area that has been the subject of much investigation is the internal world of the carer. It has been recognised that care staff cannot simply be viewed as vessels for taking in information about interventions from behavioural consultants (clinical psychologists, behaviour analysts or other multidisciplinary team members involved in designing interventions) and unquestioningly applying that information to the clients that they care for. Rather they have thoughts and feelings and these thoughts and feelings will impact upon their capacity to intervene in the recommended way. Much attention has been paid to the carer’s causal attributions about the CB, and their emotional response to it, and how these factors might influence their behaviour towards the person with the learning disability. At least two models cited in the literature, purport to explain how carers’ causal attributions, emotions and behavioural response might be interrelated. First, Weiner’s (1980) model of help-giving and second, Hastings’ (2002) stress model.

1 The terms 'care staff' and 'carers' will be used interchangeably in this report.
Although the former model was not developed specifically for application to carers of people with LD and CB, it is the most well-established of the two. Each of these models will now be considered in turn.

**Weiner's (1980) Model of Help-Giving**

Successful implementation of an intervention may depend on how carers' attribute the cause for the client's CB. According to Fenwick (1997) two sources of bias, the fundamental attribution error (Ross, 1977) and the actor-observer effect (Jones & Nisbet, 1971) can act to increase the probability that care staff will make a causal attribution about CB based on internal, hypothetical factors (e.g. client’s disposition). Such factors are not easily modifiable, when compared with external, *potentially modifiable* factors (e.g. there are no activities taking place). For example take a person with severe learning disabilities who is shouting and punching and kicking out at furniture. One carer might assume that the client has an irritable, aggressive personality and is attention seeking (internal attribution). In contrast, another carer might recognise that the client has not been out all day and has not been actively engaged in any activities and is therefore bored and frustrated as a result of lack of environmental stimulation (external attribution). Increased experience and knowledge about the communicative functions of challenging behaviour may reduce the likelihood that staff will make internal attributions (e.g. Hastings, Remington & Hopper, 1995; Oliver *et al.* 1996).

Weiner's (1980) model of help-giving has often been cited in an attempt to explain the relationship between carers’ attributions and behavioural responses (e.g. Tynan & Allen, 2002; Allen, 1999). According to this model, an internal attribution (e.g. client is attention-seeking), leads to negative affect (e.g. anger) in the carer, and consequent avoidance of the client. As in the above example, this could inadvertently increase challenging behaviour, e.g. in a client who enjoys social contact. In contrast, an external attribution would lead to positive affect (e.g. sympathy) and consequent ‘helping’ behaviour. In the above example, Weiner’s model would predict that the second carer would feel sympathy for the client and subsequently ‘help’ them (whether engaging the client in some sort of activity would constitute ‘helping’, and indeed whether ‘help’ is an appropriate term to apply when referring to carers of
individuals with learning disabilities is a topic that shall be returned to later). In addition to the internal/external dimension described above, Weiner (1980) suggested two other main dimensions that should be considered when measuring attributions; 'stability' (stable/unstable) which refers to whether every time the behaviour occurs the underlying cause is the same, and 'controllability'(controllable/uncontrollable) which refers to whether or not the person is perceived as being in control of their behaviour.

Evidence for Weiner's Model

Negative Emotions in Response to Challenging Behaviour

A strength of Weiner's model is that it acknowledges the importance of carers' emotions as well as attributions, as determinants of their responses. There is evidence to suggest that care staff experience negative emotions in response to the CB of clients, such as sadness, anger, fear and anxiety (Bromley & Emerson, 1995, Hastings & Remington, 1994). Mitchell & Hastings, (1998) initially presented carers with 18 possible emotional reactions to CB, derived from the interview transcripts obtained in Hastings (1995) and research concerning assault in psychiatric settings (e.g. Ryan & Poster, 1989). Carers were asked to rate the frequency with which they experienced these emotions when a client directed aggression toward them and when they witnessed aggression being directed toward another. These findings were then subjected to factor analysis to determine the construct validity of the scale, and two factors emerged – depression/anger and fear/anxiety.

Therefore, there is evidence to suggest that care staff do experience strong negative emotional reactions in response to challenging behaviours, as suggested by Weiner (1980). There is also evidence to suggest that the intensity and quality of emotional reaction to CB is attenuated by other factors such as the length of time that care staff have worked in the field (Hastings, 1995) and how they perceive the function of the CB (Mossman, Hastings & Brown, 2002). These two factors will now be considered in turn.

2 The dimensions of stability and controllability have received relatively less attention in the published literature than the internality dimension, hence their relatively brief mention here.
First, the time that care staff have worked in the field. Hastings (1995) conducted a study involving semi-structured interviews with 19 care staff of people with severe learning disabilities and CB. One finding was that over time there could be a numbing of emotions when exposed to clients’ CB. For example one female carer reported “I think I’ve just become hardened to it (the CB), it doesn’t make me feel anything now” (Hastings, 1995, p315). The more recent findings of Hastings, Tombs, Monzani & Boulton (2003) were consistent with this. They used an experimental design to compare experienced care staffs’ and naïve students’ ideas regarding the cause of self-injurious behaviour (SIB) and their emotional reactions to it. They found that care staff reported fewer negative emotions than the students.


The majority of studies attempting to measure care staffs’ emotional reactions to CB appear to have utilised quantitative methodologies whereby participants must confine their reporting of type and intensity of emotional reaction to a set of predefined categories (e.g. Bromley & Emerson, 1995; Mossman et al. 2002). There have been fewer studies utilising qualitative methodology, such as semi-structured interviews (Hastings, 1995, Hawkins, Allen & Jenkins, 2005). These qualitative, interview based studies have the advantage of allowing respondents the freedom to describe their experiences from their own perspective, and can give rise to discoveries that pre-defined quantitative measures would not have catered for. Examples include Hastings’ (1995) finding that more experienced carers become numbed to the experience of CB, and the discovery by Hawkins and co-researchers (Hawkins et al.
2005) that positive, as well as negative, emotions might be experienced by care staff as they physically intervene to prevent a client’s CB.

Hawkins et al. (2005) used semi-structured interviews to find out about the emotional reactions of staff and service users following incidents of CB where staff were required to physically intervene with the service user. Staff reported negative emotional reactions such as frustration, fear and anger before having to implement the intervention, and in addition, sadness, worry, shock, boredom and self-doubt during the intervention. Afterwards there were reports of feeling drained and ‘on edge’ around the client. However, emotions reported by staff were not wholly negative – one staff member reported a mixture of negative and positive emotions during implementation of the intervention, with the positive emotions being related to asserting control and preventing harm. Such positive emotions would not be anticipated on the basis of findings of previous research studies. Furthermore, they may have remained undiscovered had quantitative questionnaires been utilised rather than semi-structured interviews, since quantitative questionnaires, if devised on the basis of previous findings, would presumably only contain categories pertaining to the experience of negative emotions.

Relationship between attributions, emotions and behaviour
Sharrock, Day, Qazi & Brewin (1990) and Dagnan, Trower & Smith (1998) attempted to apply Weiner’s model of helping behaviour to paid carers of people with learning disabilities and challenging behaviours. Although some evidence was found for a direct relationship between carers’ causal attributions and their subsequent negative emotional reactions as Weiner’s model would predict, the relationship between these constructs and behaviour was found to be mediated by another variable – ‘optimism’ (Garety & Morris, 1984). Specifically, if the cause of the behaviour was regarded as unstable over time it would also be regarded as having greater potential for modification, which led carers to feel more optimistic about the potential for change and hence more likely to engage in ‘helping’ behaviours. In a later study, Hill & Dagnan (2002) suggested that the coping style adopted by the carer might act as an additional mediating factor in determining the relationship between attributions, emotions and behavioural response.
Criticisms of Weiner’s Model

Before launching into a critique of Weiner’s model of help-giving, it should be emphasised that this model was not developed to explain the behaviour of care staff of people with learning disabilities, or indeed care staff in general. Rather, it has been applied and therefore extrapolated to this population. Nevertheless, Weiner’s model of help-giving, applied as it has been to help explain and predict the behaviour of care staff of people with learning disabilities and CB, has received some empirical support (e.g. Stanley & Standen, 2000; Dagnan, et al. 1998). However, there have also been conceptual criticisms. Dagnan et al. (1998) and more recently, Jones & Hastings (2003) have questioned the ambiguity of the notion of ‘helping’ and have highlighted that further consideration needs to be given to exactly what constitutes ‘helping’ and ‘not helping’. Both sets of researchers highlight the possibility that ‘helping’ could inadvertently reinforce the challenging behaviour, such as when the staff member actively ‘helps’ an individual whose challenging behaviour is motivated by a desire for attention by giving them attention. Therefore the crucial point is to understand why staff may behave in ways that maintain challenging behaviours, rather than whether or not they ‘help’ the person engaging in the challenging behaviour (Jones & Hastings, 2003).

In addition the appropriateness of a construct entitled ‘helping’ is questionable, since such constructs would appear to conflict with the notion of empowering those with LD advocated by PBS approaches. PBS advocates assistance and support in developing the person’s functional independence, whereas the term ‘helping’ implies a desire to do things for the individual without the long-term goal of developing their own ability to function as independently as possible.

Jones & Hastings (2003) have also criticised Weiner’s model for restricting the potential range of emotional reactions to challenging behaviour to two possibilities; anger or sympathy. As the research outlined above indicates, carers have reported experiencing a range of emotions such as frustration, shock, fear, and even positive emotions (Hawkins et al. 2005). Therefore anger and sympathy may not be fundamental in predicting subsequent behaviours.
Jones & Hastings (2003) failed to find support for the relationships between attributions and behaviour hypothesised by Weiner, despite modifying the model to measure emotional reactions more commonly reported by staff involved in the care of people with LD and CB (fear and anxiety, depression and anger rather than simply anger or sympathy – Mitchell & Hastings, 1998), and measuring ‘helping behaviour’ more explicitly in terms of what the helping behaviour would comprise of. Other researchers have also failed to find evidence to support the constructs and relationships purported by Weiner’s model (Wanless & Jahoda, 2002; Rose, 2004). Wanless & Jahoda (2002) compared responses of staff to hypothetical vignettes with their responses to real life incidents of challenging behaviour. Their 38 participants were day centre staff rather than daily carers. Neither method produced findings in support of Weiner’s model – although attributions and emotions were linked as the model suggests, there was little evidence linking attributions and emotions to carers’ actual behavioural response to the CB.

*Evidence for Weiner’s model – a summary*

Although the purported links between attributions and subsequent emotions have received some empirical support (e.g. Dagnan et al. 1998; Wanless & Jahoda, 2002; Rose, 2004), the links between these key constructs and behaviour are not direct as Weiner’s model would suggest. Rather, studies have found the relationships either to be indirect and mediated by additional variables such as optimism (Sharrock et al. 1990) and coping style (Hill & Dagnan, 2002) or absent (Wanless & Jahoda, 2002; Jones & Hastings, 2003; Rose, 2004).

*Hastings (2002) Model of Staff Stress and Burn-Out*

Hastings (2002) has proposed an alternative to Weiner’s model in which negative emotional reactions to CB play a key role. He notes the importance of considering levels of stress in care staff, because stress has been found to lead to higher levels of staff absenteeism and turnover (e.g. Rose, 1995) which leads to lack of continuity of care, compounding clients’ behavioural problems (e.g. Clarke-Stewart, Vandall, McCartney, Owen & Booth, 2000). Staff under higher levels of stress at work have
also been found to interact less and engage in less positive interactions with clients (Rose, Jones & Fletcher, 1998), which may further contribute to CB, especially if the CB functions to elicit social interaction. Hastings proposes that CB causes staff to experience stress, but that this relationship is mediated by the degree to which care staff experience negative emotional reactions in response to CB.

Evidence for Hastings’ Model (2002)
As outlined above, there are some published studies supporting the contention that staff experience negative emotional reactions to challenging behaviour (Rose, Horne, Rose & Hastings, 2004, Hawkins et al. 2003, Stanley & Standen, 2000 and Mitchell & Hastings, 1998). In addition, there is some evidence supporting a link between staffs’ negative emotional reactions to CB and their levels of self-reported burnout (Mitchell & Hastings, 2001; Rose et al. 2004). For example Mitchell & Hastings (2001) asked 83 care staff to complete a self-report questionnaire designed to measure their emotional responses to aggressive behaviours, their preferred coping strategies and whether they experienced burnout. They found that coping strategies that involved disengagement were predictive of emotional exhaustion and reduced feelings of accomplishment on the part of carers. They also found that emotional reactions were related to feelings of burnout – Maslach Burnout Inventory constructs of ‘depersonalization’ and ‘emotional exhaustion’ were significantly related to ‘depressed/anger’ emotions. Mitchell & Hastings’ (2001) findings suggest that care staffs’ coping strategies may influence their experience of negative emotions. In addition to the influence of coping strategies, Hastings & Brown (2002) found evidence to suggest that high levels of self-efficacy protect against the experience of negative emotional reactions.

Rose et al. (2004) got care staff to rate their typical emotional reactions to real life incidents of CB that they had experienced, and they also completed the Maslach Burnout Inventory in relation to these incidents. This procedure was then repeated with another group of care staff but with the focus on hypothetical vignettes rather than real life incidents. Consistent with the findings of Mitchell & Hastings (2001), Rose et al. (2004) found that across both designs negative emotional reactions to
challenging behaviour were significantly related to the Maslach burnout dimensions of
depersonalisation and emotional exhaustion.

**Criticisms of Hastings’ Model**

Hastings himself notes that available evidence for a causal link between CB and stress in care staff is weak (Hastings, 2002). In addition, although the model suggests that challenging behaviours might be maintained or increased through high rates of absenteeism and staff turnover, or by care staff interacting less often or less positively with clients, these purported relationships appear to be fairly indirect and ambiguous. As such they are likely to be influenced by unidentified and therefore potentially confounding mediating factors. Hastings (2002) suggests that the relationship between the experience of challenging behaviours and stress, or that between challenging behaviours and emotional reactions of care staff, may be influenced by a number of psychological factors such as coping style (Mitchell & Hastings, 2001; Hill & Dagnan, 2002) and self-efficacy (Hastings & Brown, 2002). Hastings (2002) acknowledges that these and possibly other variables need to be explored further to allow for further refinement of the model.

On a conceptual level, it could be argued that stress, by definition, is itself a negative emotional reaction, and therefore it could be difficult to define and measure stress, and its influence on behaviour, independently of other negative emotional reactions.

**Care Staffs’ Knowledge About PBS Principles**

One factor that has been cited as potentially influencing how care staff understand the cause of CB and their subsequent willingness to implement behavioural interventions concerns their level of knowledge regarding PBS principles. Researchers have noted that one factor hindering the widespread usage of PBS is the lack of staff trained in its principles (e.g. Allen *et al.* 2005; Baker & Shepard, 2005). Even before the current dominant model, researchers were identifying care staffs’ lack of knowledge about behavioural principles as a factor influencing their inability to implement recommended interventions. For example Emerson & Emerson (1987) found that front-line staffs’ failure to implement effective behavioural interventions was closely related to their lack of knowledge of behavioural principles. Hastings (1995) in his
interview study, found that the responses reported by care staff were often apparently incongruent with their explanations regarding the cause of the CB. He suggested that this may indicate a lack of understanding of behavioural theory and methods. As mentioned previously, Hastings et al. (2003), found that care staff experienced in the care of people with LD and CB were more likely to understand the cause of a client’s SIB in behavioural terms than naïve students were. Of relevance here, the authors suggested that this may imply that formal staff training programmes and/or exposure to CB during the course of their work may lead care staff to develop a more sophisticated understanding of causal mechanisms for CB based on behavioural principles.

Formal staff training programmes (for example the Strategies for Crises Intervention and Prevention or ‘SCIP’ course, OMRDD, 1988) are one potential source of carers’ knowledge regarding PBS, including the behavioural approach to understanding clients’ challenging behaviours. Indeed, the widespread application of PBS is heavily reliant on such training programmes to help equip front-line care staff with the necessary competencies (e.g. Dench, 2005; Hastings, 2005; Baker & Shepard, 2005). Hastings & Remington, (1994) categorised staff training programmes as a formal aspect of the service culture in which staff work, in contrast to informal aspects such as verbal advice from other staff. Hastings & Remington (1994) proposed that the formal and informal culture of the service within which care staff work is one important factor affecting how they respond to the CB of clients. Participants in Hastings’ (1995) study reported that an important source of their knowledge about CB was learning from existing staff members, for example one participant reported that “It really pays off to listen to the people who’ve worked with them for a long time” (Hastings, 1995, p312). Other authors have subsequently also employed qualitative methodologies to continue to explore the influence of staff culture on carers’ responses to CB (Heyman, Swain & Gillman, 1998; Todd & Shearn, 1999; Whitworth, Harris & Jones, 1999). Findings from these studies suggested that care staff view the everyday practices developed informally within their teams as having a greater impact on their responses to CB than formal service policies. These findings also suggest that advice from outside of the staff team (such as from external
behavioural consultants) is not valued as highly as staff find it difficult to implement and feel that they know the client better than professionals from external agencies.

One study that illustrates the effect of informal staff cultures is that conducted by Noone et al. (2003). These researchers carried out an experimental study to demonstrate the effects of prior verbal information about a client’s CB on the causal attributions of participants who had no prior experience of working with people with LD. Participants listened to verbal descriptions about a client with CB, before watching a video clip of the client exhibiting CB. The content of the verbal descriptions of the client varied across four conditions (four combinations of ‘consistency’ — CB stable/unstable across situations, and ‘control’ — behaviour described as within the client’s control/not within his control). Naïve participants were chosen because the authors felt that they would more closely resemble new staff members who would be more susceptible to the prevailing staff culture. The content of the verbal information given prior to the video clip was found to influence participants’ explanations of the cause of the CB, which they were asked to report on a pre-designed measure (Attributional Style Questionnaire, Peterson et al. 1982) after seeing the video. The authors suggested that their findings supported the contention that what staff say about a client’s CB is likely to influence how staff perceive subsequent incidents of CB.

In summary, PBS is currently reliant on formal staff training for its dissemination to front-line care staff. However, the available evidence suggests that care staff acquire their knowledge and develop their skills informally through contact with colleagues within the workplace environment.

The Impact of Gender — a Previously Neglected Topic?
One potential aspect of carers’ experience that is not explicitly incorporated within any of the models reviewed above is the issue of gender. Indeed, a number of researchers within the field appear not to have given consideration to the issue of gender, despite carers highlighting it as a significant factor in their understanding of a client’s challenging behaviour (e.g. Hastings, 1995; Bromley & Emerson, 1995). For example, Hastings (1995) utilised qualitative methodology in an exploratory study
partly aimed at finding out why care staff respond to people with learning disabilities and challenging behaviour in ways that are not conducive to rehabilitation. Participants’ accounts showed that their responses were not necessarily related to their attributions regarding the cause of the challenging behaviour, and this was attributed to a lack of knowledge regarding behavioural approaches. Although one of Hastings’ participants explicitly referred to the importance of the client’s gender in their understanding of her behaviour (see Hastings 1995 p305), Hastings did not refer to this. Other researchers in the field have also given gender little or no consideration (e.g. Dagnan et al. 1998; Stanley & Standen, 2000).

Sequeira & Halstead (2001) found evidence to suggest that women and men with challenging behaviour were treated differently by carers, with women more likely to receive tranquillisation and men more likely to receive seclusion as an intervention. It has been suggested that women are subjected to more invasive treatment by carers because their challenging behaviour is regarded as more deviant than men’s according to gender stereotypes (e.g. Scotti et al. 1991). Clements, Clare & Ezelle (1995) suggest that if carers ignore the impact of gender then there is a danger that they may fail to understand how the different needs of men and women are manifested in challenging behaviours. Given that gender would appear to be an important (if hitherto hidden) factor, this investigation will attempt to explore whether carers feel that gender impacts on their understanding of clients with learning disabilities and challenging behaviour, and if so, in what ways. It would appear particularly important to explore the impact of gender in the light of the Department of Health’s Strategic Development plan “Women’s Mental Health: Into the Mainstream” (Department of Health, 2003).

The Present Study

Although alternative models are beginning to be considered (Jones & Hastings, 2003, Hastings, 2002) the majority of published studies (at least those utilising quantitative methodologies) appear to have been based on Weiner’s model of help-giving. The evidence outlined previously suggests that prevailing models (i.e. Weiner, 1980 and Hastings, 2002) have limitations.
Studies investigating the usefulness of Weiner's model (e.g. Dagnan et al. 1998; Stanley & Standen, 2000; Tynan & Allen, 2002; Jones & Hastings, 2003) have chosen to use hypothetical accounts of people with learning disabilities and challenging behaviour. These hypothetical accounts have been utilised within a quantitative approach whereby carers were asked to categorise their attributions and behavioural responses according to pre-existing measures. Allen (1999) in a review of the literature, suggested a need for research examining these factors in relation to real-life instances of challenging behaviour rather than hypothetical vignettes. Wanless & Jahoda (2002) suggest that abstract, hypothetical vignettes are unlikely to be of personal significance to care staff, and will therefore be unlikely to resonate personally with care staff. It is argued that such vignettes will therefore fail to evoke the rich and varied emotional and cognitive reactions that real incidents are likely to evoke in participants. As mentioned previously, they compared day care staffs' responses to hypothetical vignettes with their responses to real life incidents of CB that they had witnessed and found that real life incidents of aggression prompted more negative evaluations of the client and stronger emotional reactions (Wanless & Jahoda, 2002). In addition, Sequeira & Halstead (2002) suggested that the use of pre-existing measures risks eliciting opinions that are not actually held by the carer, and encourages the researcher to impose their own biases on the carer.

There is no doubt that the studies utilising quantitative methods outlined in this paper have made a useful contribution to furthering our understanding of why care staff may not implement PBS based interventions in the way intended by those designing those interventions. However there is still a need for a more in depth exploration of the phenomena if the aim is to capture and in some way understand the likely complex and subtle nature of carers' attributional processes, emotions and behavioural responses and other factors which impact upon their ability to implement interventions.

The present study aimed to address these concerns by using a qualitative method – Interpretative Phenomenological Analysis (IPA – Smith, 1996; Smith, Flowers & Osborne, 1997; Smith, Jarman & Osborne, 1999) to explore carers' experiences, with regard to real-life instances of challenging behaviour that they have witnessed. Sequeira & Halstead (2002) noted some important advantages of using a qualitative
approach, e.g. that it enables researchers to learn about peoples' perspectives without making prior assumptions about how a particular phenomenon is experienced, and allows researchers to remain open to aspects of experience that they did not anticipate. IPA was the qualitative method of choice for this investigation, since emphasis is placed on developing an 'insider's perspective' (Conrad, 1987). Thus the participant's own experiences are central. As already noted, previous researchers in this area have employed quantitative measures to find evidence for Weiner's (1980) model of help giving (e.g. Dagnan et al. 1998; Stanley & Standen, 2000), or have used the model to explain their findings (e.g. Tynan & Allen, 2002). Still others have proposed alternative models to explain carers' responses to CB (e.g. Hastings, 2002). It would perhaps be fruitful to discover in what ways carers' own accounts of their experiences of CB are similar or different to these models. It may be that carers place emphasis on aspects of experience that are not incorporated within existing models.

In summary, a qualitative study was proposed, using IPA. Semi-structured interviews (Smith, 1995) were conducted with professional carers who had been involved in an incident of challenging behaviour. The main aim of the study was to find out more about how the carers themselves experienced challenging behaviour, including their understanding of its cause and their emotional reactions to it, and how their understanding was related to the way in which they responded (if at all). A second aim was to elicit carers' ideas about where and how they acquired the knowledge that they had about clients' CB, and their ideas about the usefulness of various sources of knowledge. A subsidiary aim was to explore carers' understanding of the effect of gender on their interaction with the client during the specific incident of CB that they will chose to describe.

Interviews were audiotaped and transcribed, and a series of established steps were used to analyse the transcripts, consistent with IPA (e.g. see Willig, 2001). The quality of the research was evaluated using published criteria for the evaluation of qualitative research (e.g. Elliott, Fischer & Rennie, 1999 and Yardley, 2000).
METHOD

Research Design
Researcher's Interpretative Framework

I spent a six month placement with the Community Learning Disabilities Team of which the Challenging Needs Service (CNS) was a part, approximately one year and three months before I began data collection. Although I was not directly involved in the work of the CNS, I did attend their weekly meetings. Therefore I had some knowledge of the work of the service. This included information about the clients referred and their challenging behaviours, the beliefs of members of the CNS about the origins and functions of those challenging behaviours, and information about the interventions designed to help reduce the challenging behaviours. During this placement I was able to complete the SCIP training course. During this course I learned about beliefs of experts in the field regarding the escalation of challenging behaviours and the benefits of early intervention to prevent such escalation, the importance of identifying antecedent events (triggers) to enable early intervention, and how to implement reactive physical interventions in a safe, respectful way.

Personally, two of my own family members have learning disabilities, and although neither show challenging behaviours, one family member lived in a home with other people with LD who did show challenging behaviours, which I sometimes observed when I visited my relative.

Based on these experiences I hold the belief that the majority of challenging behaviours are functional, in that they serve as a way of communicating a need which the person is unable to communicate in a more adaptive way. I believe that interventions based on differentially reinforcing more adaptive means of communication of the kind consistent with PBS should be effective in enabling the person to become less reliant on CB as a means of communication. I also believe that being involved in the care of a person with learning disabilities who exhibits challenging behaviours could be a very difficult, stressful role, because of the nature

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3 In keeping with the reflective nature of the work, the researcher has chosen to refer to herself in the first person
of the behaviours themselves and the impact that they could have on the emotional well-being of the carer.

**Procedure**

**Ethical Approval**

Ethical approval was obtained from one Local Research Ethics Committee (see Appendix 1) and from the University Advisory Committee on Ethics (see Appendix 2). The Research Governance Manager for the locality within which the research was being conducted was also contacted with a view to obtaining Research Governance approval, but she confirmed that this was not necessary due to the nature of the research (see Appendix 3).

**Recruitment of Participants**

*Sampling Method*

Purposive sampling was employed in order to obtain a sample homogenous to the extent that the research question was of relevance to them all and they had experience of the phenomenon under investigation such that they could provide an insight into their psychological experience of the phenomenon (Osborn & Smith, 1998).

*Inclusion Criteria* ___________

Participants were deemed suitable for inclusion in the study providing they met the following criteria:

- The paid carers must have had regular (i.e. daily) contact with a person/persons with learning disabilities and challenging behaviour during the course of their work
- They must have witnessed or been involved in an incident of challenging behaviour
- They had to be sufficiently proficient in spoken English to be able to participate in the interview.
Recruitment Process
The Community Learning Disability Team (CLDT) — and the Challenging Needs Service (CNS) contained within it — provide a service to clients with learning disabilities and their carers, many of whom live in houses in residential areas of the community. These houses are owned and managed by independent sector organisations, who also employ paid carers (‘support workers’) to support their residents. I met with my Field Supervisor (also Head of the CNS) in order to identify a company whose houses were known to the CNS because they housed people with learning disabilities and challenging behaviours. I then wrote to the management team of this company to explain the aims of the research (see Appendix 4), and later spoke to the Operations Manager and Support and Development Manager by phone. These Managers gave the names of the Managers of three homes, each of which housed more than one person with challenging behaviours. I then sent these Home managers cover letters (see Appendix 5) and information sheets (see Appendix 6) about the study, and later phoned them, with a view to obtaining the names of all the support workers within each home, who could then be sent letters of invitation and information sheets via their workplace. However, the Home Managers declined to give the names of the support workers, instead preferring to put the details of the study on notice boards together with a ‘sign-up’ sheet. I then telephoned the Home managers to find out the names of all interested support workers. No support workers from the first Home that I had approached wanted to participate, six support workers from the second home expressed an interest in participating and two from the third home. These support workers were then sent a letter inviting them to take part (see Appendix 7), an information sheet and a reply slip on which they were requested to provide contact details so that I could contact them to arrange an appropriate time to conduct the interviews. All but one of the support workers who had expressed an interest agreed to participate, resulting in a total of seven participants at this stage. All three Home managers had expressed a willingness to participate when initially contacted. Therefore, because of the low uptake from two of the homes approached, and because all Home Managers met the inclusion criteria, they were also invited to participate in the study. This resulted in a total sample size of ten participants (demographic information is presented in the Analysis section).
Data Collection

*Semi-Structured Interview*

The questions and prompts contained within the semi-structured interview schedule, and the order in which they were presented, was tentative, since the interview schedule is not meant to be prescriptive, nor is it meant to act merely as a vehicle to enable the researcher to check her own preconceived notions (e.g. Osborn & Smith, 1998). Rather, the idea is for the participant to give their own view, and if they should highlight issues that the researcher did not anticipate (e.g. Sequeira & Halstead, 2001), there should be enough flexibility to enable these to be explored.

*The Interview Schedule*

I met with my Field Supervisor to gain an insight into important issues that he had become aware of through his knowledge of the research literature and direct experience of working with people with challenging behaviours and their carers (support workers). At this stage I also reviewed published literature investigating the experiences of carers of people with LD and CB, to further define important areas to cover in the interview. Individual interview questions and prompts were crafted under the guidance of a senior research tutor experienced in IPA, to ensure that they were sufficiently open-ended and non-leading. The tutor and the Field Supervisor then checked the entire interview schedule and alterations were made where necessary. The interview schedule was then piloted on two colleagues who had experience of working with people with learning disabilities and challenging behaviour, and slight amendments to wording (which did not alter content) were made on the basis of their feedback (for copy of interview schedule see Appendix 8).

*Conducting the Interview*

Interviews were conducted at each participant’s place of work during their working hours. Every effort was made to ensure that interviews were conducted in a quiet room away from distractions. Before commencing the interview, participants were asked to sign a consent form to indicate their willingness to take part and their consent to having the interview audiotaped (see Appendix 9). They were then asked to complete a sheet containing a number of questions designed to elicit background
demographic information (see Appendix 10). Interviews lasted between 45 minutes and two hours.

**The Analytic Process**

Interviews were transcribed verbatim (for an example of an interview transcript see Appendix 11). Transcripts were then subjected to analysis in accordance with the principles of IPA (e.g. Smith, 1996; Smith, Jarman & Osborne, 1999; Willig, 2001). In the interests of transparency (Smith, 1996) a detailed account of the analytical procedure is described below.

The first interview transcript was read and re-read to allow me to engage with the text. Then notes were made in the left hand margin about anything that struck me as significant, based on either the content, the process of the interview, links with other parts of the transcript or links with existing theory. I then went back through the transcript and started to document emerging themes in the right hand margin, based on the left hand margin notes. Throughout this process I checked for evidence of the emerging themes in the text. At this stage of emerging themes I was able to use psychological terminology if that was appropriate to encapsulate the theme. As the themes emerged I noted them on a large piece of paper, and started to look for commonalities between themes which may indicate that they could be clustered together. As themes were clustered together a list of master themes started to become apparent. In order to ensure that emerging themes remained ‘grounded’ in the data, I lifted quotes from the transcript and wrote them together with the theme to which they belonged on the separate piece of paper, thereby building up a ‘directory’ of quotes in support of each emerging theme. When the analysis of the first transcript was complete, I moved on to the second transcript. Again the transcript was read and re-read and left-hand margin notes made. I was then able to find evidence for existing themes, and quotes were added to further substantiate existing themes. This process continued for the other transcripts. Throughout this process I remained open to the possibility that new themes might emerge in subsequent transcripts. This did occur, and necessitated that I go over previous transcripts to look for evidence of these new themes in the data. Some themes were also dropped from the emerging list of master themes as they were not adequately supported by the data.
Evaluative Criteria
Since criteria for evaluating the quality of quantitative research studies do not seem entirely appropriate for the evaluation of qualitative research studies, alternative criteria have been proposed that can be specifically applied when evaluating the quality of qualitative research (Yardley, 2000; Elliott et al. 1999). For example, the following criteria could be applied to assess the rigour of this study.

Credibility
One way to check the credibility of emerging themes and relationships between them is to have independent researchers analyse one or more transcripts. Two fellow researchers independently analysed one transcript and then met with the researcher to discuss the emerging themes, links between them and supporting data. This allowed me to check that there was sufficient evidence in the interview data to support my emerging list of master themes.

Owning One's Perspective
I should be able to demonstrate that I am aware of my own values and assumptions and how they have impacted on the research process through the keeping of a reflective diary. I have kept a reflective diary throughout the research process and this is available upon request. I have also described my own experience of the phenomenon under investigation and my associated beliefs earlier in this report, and have reflected on my impact upon the research process in a later section.

Situating the Sample
The characteristics of the participants are described at the beginning of the Analysis section, to assist the reader in judging the variety of situations and people to which the findings could apply.
Grounding in Examples

Quotes are provided throughout the Analysis section to illustrate how the themes grew out of the original transcript texts. It is hoped that the quotes will allow the reader to evaluate the goodness of fit between the data itself and my understanding of the data.
ANALYSIS

Participants
All participants and all people with learning disabilities referred to during interviews have been given pseudonyms to ensure that they remain anonymous. Table 1 shows participants’ demographic information. There were ten participants in all, six males and four females. The mean age of the participants was 40.8 years (range 27 – 64 years). Two participants had no formal qualifications, and two were educated to at least degree level, with the rest of the participants falling somewhere in between with regard to educational qualifications. With regard to the time spent working with people with learning disabilities, three had spent under one year working in the area, five had spent between one and six years, and two had spent at least fifteen years working with people with learning disabilities. The ethnic origin of eight participants was white-British, with one participant originating from India and another describing herself as of Asian European origin.

Identified Themes
Table 2 shows the superordinate themes together with their constituent themes. As the analysis progressed, some themes identified initially seemed less central to the aims of the study or were not well supported in the data and will therefore not be presented. An attempt has been made to order the themes so that they present a clear, coherent narrative. Inevitably, some themes are a reflection of the questions employed in the interview schedule (Coyle & Rafalin, 2000). As Table 2 shows, three superordinate themes emerged from the analysis. These, together with their constituent themes, are discussed in turn below.

Superordinate theme 1 - Understanding of CB
Several themes emerged from participants’ rich verbal illustrations of the way in which they understood incidents of CB. Four themes emerged and were clustered together to form the first superordinate theme, ‘Understanding of CB’. These were participants’
<table>
<thead>
<tr>
<th>ID</th>
<th>Time in Years</th>
<th>Time Working</th>
<th>Position Held</th>
<th>Education Level</th>
<th>Ethnicity</th>
<th>Age</th>
<th>Gender</th>
<th>Pseudonym</th>
<th>Participant Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>1</td>
<td>6 months</td>
<td>HND</td>
<td>A Level</td>
<td>White-British</td>
<td>34</td>
<td>F</td>
<td>Helen</td>
<td>1</td>
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<tr>
<td>2</td>
<td>6</td>
<td>6 years</td>
<td>HM</td>
<td>I</td>
<td>White-British</td>
<td>34</td>
<td>F</td>
<td>Alison</td>
<td>2</td>
</tr>
<tr>
<td>3</td>
<td>6</td>
<td>6 years</td>
<td>SW</td>
<td>HSC</td>
<td>Post-Grad</td>
<td>35</td>
<td>M</td>
<td>Simon</td>
<td>3</td>
</tr>
<tr>
<td>4</td>
<td>16</td>
<td>1.5 years</td>
<td>SW</td>
<td>Pre-CEE</td>
<td>White-British</td>
<td>50</td>
<td>M</td>
<td>Michael</td>
<td>4</td>
</tr>
<tr>
<td>5</td>
<td>1</td>
<td>5 months</td>
<td>SW</td>
<td>GCSE</td>
<td>Devee</td>
<td>32</td>
<td>M</td>
<td>Daniel</td>
<td>5</td>
</tr>
<tr>
<td>6</td>
<td>1</td>
<td>5 months</td>
<td>SW</td>
<td>A Level</td>
<td>White-British</td>
<td>27</td>
<td>M</td>
<td>Terry</td>
<td>6</td>
</tr>
<tr>
<td>7</td>
<td>5</td>
<td>6 months</td>
<td>SW</td>
<td>GCSE</td>
<td>White-British</td>
<td>64</td>
<td>M</td>
<td>Shefied</td>
<td>7</td>
</tr>
<tr>
<td>8</td>
<td>5</td>
<td>6 months</td>
<td>SW</td>
<td>A Level</td>
<td>White-British</td>
<td>29</td>
<td>F</td>
<td>Corned</td>
<td>8</td>
</tr>
<tr>
<td>9</td>
<td>15</td>
<td>10 months</td>
<td>SW</td>
<td>I</td>
<td>Asian-European</td>
<td>56</td>
<td>F</td>
<td>Olivia</td>
<td>9</td>
</tr>
<tr>
<td>10</td>
<td>4</td>
<td>18 months</td>
<td>HM</td>
<td>I</td>
<td>White-British</td>
<td>37</td>
<td>F</td>
<td>Emily</td>
<td>10</td>
</tr>
</tbody>
</table>

Table 1: Demographic information of participants. (G = Gender; HM = Home Manager; SW = Support Worker)
Table 2: Superordinate Themes and Themes

<table>
<thead>
<tr>
<th>Superordinate Theme</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Understanding of CB</td>
<td>- What Constitutes CB</td>
</tr>
<tr>
<td></td>
<td>- Understanding of Cause</td>
</tr>
<tr>
<td></td>
<td>- Perceived Elusiveness of Triggers</td>
</tr>
<tr>
<td></td>
<td>- Emotional Reactions</td>
</tr>
<tr>
<td>Attempting to Intervene</td>
<td>- Reactive Strategies</td>
</tr>
<tr>
<td></td>
<td>- Barriers</td>
</tr>
<tr>
<td>Sources of Knowledge &amp;</td>
<td>- Formal Training &amp; Written Guidelines</td>
</tr>
<tr>
<td>Support</td>
<td>- Informal Contact with Colleagues</td>
</tr>
<tr>
<td></td>
<td>- Hands-On Experience</td>
</tr>
</tbody>
</table>
understanding of what constitutes CB, their understanding of the cause of the CB that they had witnessed, the perceived elusiveness of trigger events and their emotional responses to the CB. For some participants, understanding of cause appeared to be related to emotional responses. For other participants, the perceived elusiveness of trigger events seemed to be related to their emotional responses.

What Constitutes CB

Three participants conceptualised challenging behaviours in terms of a range of severity, with verbal abuse typically being described as the mildest form of CB and physical aggression as the most severe. For example, Allegra implied a continuum of severity with physical abuse as the most severe. She also distinguished between different forms of physical aggression. "I suppose it can range anything from...just verbal abuse....to physical, and that can be directed at peers, staff or inanimate objects like um...doors, furniture..." (Allegra)

These participants' conceptualisations could be viewed as being broadly consistent with definitions of CB that are available in the published literature such as that of Emerson (1995 – see Introduction) and Quereshi & Alborz (1992).

However other participants' descriptions of what constitutes CB did not imply that CB could be manifested in terms of a range of topographies or levels of severity. These participants' descriptions were less similar to definitions available in the published literature. For example Brent, when talking about the challenging behaviour of a particular client, disagreed with his colleagues' view that the client's violent behaviour should be classified as challenging. He felt that the CB came before the violence, but he was vague about what form this CB took.

"Virtually everyone that's here at the moment including.....view his challenging behaviour as when he becomes violent.....whereas I think the challenging behaviour is what's leading up to that, because he doesn't know how to....to deal with it" (Brent).

Siegfried expressed his view of what constitutes challenging behaviour in terms of the poor personal hygiene of some clients "Umm....I think their personal habits, their
hygiene habits and so on. Refusal to take baths, clean themselves, that type of thing. That's probably, the, yeh, problem, yeh” (Siegfried). He went on to qualify why this should be classed as challenging behaviour – because it presented a challenge to the staff

“I call it challenging behaviour because its, err, challenging to us here. The staff are trying to get their clients to do things, it's a challenge to us” (Siegfried).

In comparison to participants like Allegra, participants like Brent and Siegfried appeared to conceptualise CB in ways that were idiosyncratic and relatively less similar to definitions available in the published literature. Therefore, there appears to be a discrepancy within the group between, on the one hand, participants whose descriptions ‘fit’ with definitions available in the published literature, and, on the other, views that are less consistent with such definitions. Assuming that clinical psychologists and other MDT members endorse widely accepted definitions that are available in the literature such as that of Emerson (1995), variations in carers’ own particular conceptualisations of what constitutes CB could have important implications. For example, if carers conceptualise CB differently from MDT professionals, carers’ acceptance of the legitimacy of interventions could be reduced. This issue will be returned to in the discussion.

**Understanding of cause**

Participants were asked to describe a specific incident of challenging behaviour that they had witnessed, and to explain what they thought had caused that challenging behaviour.

Some participants gave complex explanations of cause based on a variety of contributory factors and their interactions. Contributory factors that participants spoke about included past life events “It was something that happened to her or something she witnessed....um....the lady in particular had um...experienced quite a lot of trauma in her life” (Allegra), and the way in which the client processed information in relation to their current environment “...I think a lot of her challenging needs was down to....the way she absorbs information, the way she....sorted it out and then she had to bring it to the surface in her own time” (Allegra). These participants also included explanations of how such factors interacted to maintain the CB. For
example one participant, Fleur, spoke about her client’s belief that using the toilet was dirty, and how this belief led him to resist using the toilet, so that when he did use the toilet the resultant mess meant that his belief in the dirtiness of the act was reinforced.

“*He thinks it’s a dirty thing to do, he thinks that its not right, it’s a dirty thing to do...and also, that is reinforced ‘cause when he does go, he has....he doesn’t...he has accidents, which makes him feel even worse! It’s a...it’s a never ending cycle*”  
(Fleur)

These participants’ explanations incorporated information about the client’s past life experiences, their individual beliefs and preferences and their characteristic ways of understanding what is going on in their immediate surroundings. They also incorporated explanations of how these factors interacted with the client’s current residential environment to produce and maintain the challenging behaviours. As such these explanations bore the hallmarks of complex, sophisticated psychological formulations of clients’ difficulties.

Other participants’ causal explanations were less complex, but again the way in which the client processed information with regard to their immediate surroundings seemed to feature in participants’ explanations. For example Ashton, in describing events preceding a specific incident of aggression exhibited by his client, said “…*well it doesn’t register, you’ve got to pay for this. All he registers is you’ve taken his money out of his purse and given it to the lady behind the counter*”  
(Ashton)

Some participants’ causal explanations implied that they held the client responsible for their challenging behaviour. These participants seemed to believe that the client had acted in that way intentionally. For some, like Brent and Leroy, this was related to the client’s ability to exploit the ‘system’ – the predictable routines involved in the running of the home.

“*...one of the residents – I’m his keyworker – and he knows everything back to front, and so its hard to get him to do anything...and he’ll do things deliberately*”  
(Brent).
"...and this particular resident was violent, he was an opportunist and he realised there was only one staff member here available" (Leroy).

In summary, participants' accounts varied in terms of the complexity of their understanding of the cause of the client's CB. Some participants' explanations (e.g. Allegra and Fleur) encompassed a broad range of factors and incorporated explanations of how these factors interact to produce the CB. Such explanations tended not to place responsibility on the client for their actions. In contrast, other participants' causal explanations (e.g. Brent and Leroy) were more restricted in that they tended to place emphasis on the client's personality without considering a range of potential influencing factors. These narrower explanations perhaps imply a more limited awareness of the range of factors that might be contributing to the client's CB. These more restricted explanations of cause were more likely to place blame on the clients themselves for their challenging behaviour, rather than to aspects of their environment.

**Perceived Elusiveness of 'Triggers'**

The PBS approach advocates the existence of 'triggers' ('warning signs') that signal the likely escalation of the client's level of agitation, culminating in the exhibition of challenging behaviour. The clinical psychologist or behavioural analyst will usually initially identify triggers in conjunction with the staff team, as part of the assessment. Information about likely triggers is then circulated to care staff, and they are encouraged to look out for them. When a trigger is identified, staff are encouraged to intervene at an early stage (for example by altering or removing the trigger or distracting the client) in order to prevent the client's level of agitation from increasing.

Several participants' accounts revealed that triggers were often perceived as extremely elusive. Participants remarked on how triggers were often so fleeting, so transient, that they were very difficult to identify and hence act upon.

"So you could play that CD one night, nothing...um, she could give the appearance of doing one thing but her mind would be racing and...and sometimes you just get a glint in the eye....and it would be that split second trigger" (Allegra)
"...it had been a good day until a few seconds before...but things like that you can't get warnings for....you can't always preempt 'cause its (participant clicks his fingers) in a second..." (Brent)

Participants strove to understand what had triggered the CB. Leroy conveyed a sense of self-doubt, a sense of uncertainty about his ability to identify the trigger “Perhaps there was something I didn't see, that could have been the trigger, perhaps if I'd had more knowledge of the residents, I might have been able to spot the trigger” (Leroy).

Accounts such as Leroy’s suggest that participants not only doubt their ability to identify triggers, but also that they place a great deal of responsibility upon themselves for failing to identify a trigger and therefore failing to intervene to prevent the situation from escalating. Allegra was concerned that she herself might have been responsible for providing the trigger “And you could analyse the ABCs (monitoring charts of antecedents, behaviours and consequences) for...you know, in the heat of the moment, you all try and keep to your guidelines, but sometimes you can slip in an extra word, that might be a trigger” (Allegra).

The elusive nature of these triggers left other participants, like Ophelia, going over the incident of CB in their minds in what seemed to be a desperate attempt to make sense of the situation. For Ophelia, this desperate attempt to make sense of the situation continued after her shift had ended and she had gone home

“Many a time, when things have happened in this house I’ve gone home and I’ve thought you know, where did we go wrong sort of thing, you know, where did, did they kick off you know and I sit there and I try to work it out, and sometimes I get no answers” (Ophelia)

Ophelia’s last remark, about getting no answers, suggests her acknowledgement that this process of mentally going over events is, at least on some occasions, futile.

To summarise, carers highlighted the elusive nature of triggers. This led them to engage in a process of repeatedly going over events in a desperate attempt to make
sense of the situation. It can be tentatively suggested that this process appeared to involve three elements; a sense of uncertainty about the situation as a whole, doubt about their own ability to identify triggers and hence intervene to stop the escalation, and concerns about whether their actions directly contributed to the onset of the challenging behaviour. Such a process of mentally going over the event to try and make sense of it, but (as Ophelia suggested) getting nowhere, seems inherently stressful. This seems particularly so when the process continues after the participant's shift has ended and they have gone home. As mentioned in the introduction, Hastings (2002) notes the importance of considering care staffs' stress levels, and this issue will be returned to in the discussion.

**Emotional Reactions**

Participants were asked to describe how they felt when they witnessed the challenging behaviour. Participants spoke about a variety of negative emotions. Some participants, like Allegra and Ophelia, said that they felt worn out or exhausted after the incident of CB. Furthermore, they linked this to going over the event in their minds to try and make sense of it, to understand why it had occurred and the part that they may have played in the onset of the CB. For both Ophelia and Allegra the process of trying to make sense of what had happened meant that they went home feeling exhausted after their shift had ended.

"But I know when I went back home on that last week I felt really worn out, you know, yeh" ..............

"Yeh, yeh, I did feel worn out, you know 'cause for the life of me I was thinking 'What have I done?' You know I've done exactly the same things over the last few months, coming and doing whatever, and all of a sudden you know this month whatever I did was wrong, do you know what I mean?" (Ophelia)

"Because its like the rules are changing (laughs) okay where did that come from? Why didn't I see that coming and...and you do, you can think to yourself...go over things you know... " ..............

"...and you can go home actually exhausted...literally exhausted and think whoo...you know, where did all that come from?" (Allegra)
Other participants spoke of their fear upon witnessing the challenging behaviour. These participants tended to attribute their experience of fear to not knowing the client very well at the time of the incident, so that they did not know what to expect. There was, therefore, a sense in which participants could not admit to feeling fearful simply because the CB was frightening to witness. Rather, there had to be some justification, some excuse for feeling 'scared'. For participants like Ashton and Conrad, not knowing the client very well, not knowing what the client was capable of, appeared to serve as justification for their fear.

“At the time a little frightened because although I’ve worked with challenging behaviour I’d never worked with this client and I didn’t know how he would react although the focus wasn’t on me” (Ashton)

“’Cause when I just started here after the induction I was really new to him during that time and that’s why I was a bit scared” (Conrad)

However, it should be noted that this interpretation, that participants feel a need to justify their fear, is made tentatively, and with an awareness of my own interpretative bias. This particular interpretation may be influenced by two particular preconceived ideas that I am aware of holding. First, my belief that it must be frightening to witness CB, and that it would be frightening regardless of the extent of one’s experience. Second, my observation that all four participants who spoke of fear were male has led me to draw on a male gender stereotype which suggests that men are perhaps generally less comfortable about admitting to feeling scared than women. Interestingly none of the female participants in the sample reported feeling fearful in response to the CB. This perhaps suggests either that they simply did not feel fear in relation to the incident that they were describing, or that they were even less inclined to admit to feeling scared than the men in the sample!

Some participants said that they felt anger or frustration toward the client when they witnessed them exhibiting the CB. These participants, like Brent for example,
explained the cause of the client's CB in terms of the client’s personality, and saw the client as being responsible for their behaviour.

"The most frustrating one for me is the second one ('bucking the system') because one of the residents – I'm his keyworker – and he knows everything back to front, and so its hard to get him to do anything... and he'll do things deliberately" (Brent)

This is in keeping with the findings of previous research studies suggesting that carers are more likely to experience intense emotional reactions in response to CB if they perceive the client as being in control of their behaviour (Dagnan et al. 1998; Stanley & Standen, 2000).

Some participants who had spoken of their anger and frustration with the client then went on to describe how they tried to conceal their emotions so as not to let their anger affect their treatment of the client. For some, like Leroy, this concealment of angry emotions was difficult

"...it does make you angry but its just part of the job you just have to obviously deal with it – its hard" .......... ....

"Its just human instinct (to feel angry) it was the wrong thing to do, unprovoked, and just human instinct, you just feel a bit angry, but obviously being a professional you don't show your anger" (Leroy)

Unlike Leroy and Conrad, who seemed to recognise and accept their feeling of anger, but nevertheless attempted to conceal it, Elspeth appeared to deny herself the opportunity to feel upset by the CB

"There's no point in becoming upset by an incident, there's no point in allowing how you personally feel to reflect on how you handle the person that's got the problem, because that would just escalate it" .......... 

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4 A part of this quote appeared earlier in the theme 'Understanding of Cause'. However it is included again here for the purpose of setting the initial part of the quote in its rightful context.
"It could be very upsetting, but it has to be water off a duck's back, it has to be"  
(Elspeth)

To summarise the theme of emotional reactions, some participants reported feeling exhausted when they went home at the end of their shift, and they related this to going over the incident in their minds, in what appeared to be a desperate attempt to understand what had happened. Other participants reported feeling fear when they witnessed the CB, and they related this to not knowing the client very well at the time of the incident, and therefore not knowing what the client was capable of. Other participants reported feeling frustrated or angry. Interestingly, these participants had previously explained the client’s CB in terms of a narrow range of factors, attributing the CB to the client’s personality and implying that the client was in control of their behaviour. This apparent relationship between certain types of causal attributions and emotions would appear consistent with existing literature (Stanley & Standen, 2000; Dagnan et al. 1998). Finally, participants also spoke about the need to conceal their anger in the course of their work, and how this was difficult.

Summary of first superordinate theme – Understanding of CB

In summary, participants’ understanding of what constituted CB varied, from descriptions that were consistent with those contained within published literature and typically endorsed by clinical psychologists and others responsible for the design of interventions, to more idiosyncratic descriptions that were less consistent with published definitions. Participants’ explanations of the cause of the incident of CB that they had witnessed varied in complexity, and participants whose causal explanations were more restricted tended to place a greater degree of responsibility on the client for their actions, and feel anger and frustration toward the client. These participants also spoke of their need to conceal their anger. Participants spoke about the elusive nature of trigger events, and this was related to a desperate attempt to make sense of the incident of CB and to understand the part that they played in the incident. Participants who tried to make sense of the situation in this way reported feeling exhausted.
Superordinate Theme 2 - Attempting to Intervene

Participants were asked to describe how they responded to the specific incident of CB that they had chosen to describe. Similar issues came up in participants’ accounts, and formed the first theme of this cluster, labelled ‘Reactive Strategies’. Participants were also asked what factors they thought acted as barriers, preventing them from implementing interventions in the recommended way. Participants’ responses gave rise to the second theme in this cluster, labelled ‘Barriers’.

Reactive Strategies

Some participants, like Brent, described an immediate need to manoeuvre themselves or others to ensure their safety in the face of the CB. “To manoeuvre myself in the kitchen so that I was in a safe area for me and in an area where I could see everything and react quickly, there’s no obstructions on the floor in the area, nothing like that” (Brent).

The amount of effort participants had to expend on initial risk management seemed to depend on how much potential there was for danger in the immediate vicinity. For example, Allegra described an occasion when her client (whose challenging behaviour typically manifested in throwing objects at people) became agitated in the kitchen. “It...it just depends how much danger there was um...other occasions she wouldn’t want to leave so you try and make the environment as safe as possible...which is turning off ovens, putting saucepans in ovens, in cupboards” (Allegra). Allegra also conveyed how quick-thinking carers need to be in assessing risk “You have to I suppose on-the-spot risk assess everything” (Allegra).

Following the initial risk assessment, the majority of participants described how they attempted to stop the client’s CB by talking to the client. For some participants, like Darius, talking had the aim of calming the client “Yeh, trying to talk him down, calm him down” (Darius). For Ashton, the talking had a different aim – to alert the client to the possible consequences of his actions “Well the first thing I said to him ‘If you break the window’ I says ‘You’re going to hurt yourself, you could even hurt yourself just keep banging it’ ‘If the window breaks, you could finish up hurting yourself, you would have to go to the hospital and then the police would be called’” (Ashton).
Several participants mentioned the need to calm the client by simply leaving them alone, for example, Elspeth "...if she tells you to go away we'll just do it and leave her until she's calmed down enough to talk to you" (Elspeth). However some participants were more active in their attempts to intervene to stop the client's CB. For example Allegra described how she attempted to remove the client from the immediate vicinity "Very calm, you just get up and you position yourself so that the others are safe, and then you would just encourage them out of the vicinity or depending on what was going on really..." (Allegra). Taking the client out of the immediate environment can also serve to distract them from the initial stimulus that triggered the CB, as Elspeth implies "Sarah wasn't watching TV but she was being quite aggressive and I think I called her through to the office, she wanted, for something...she wanted to do something and it was something she would like to do" (Elspeth).

None of the participants explicitly linked their response to the incident of CB to their feelings about it. Furthermore, there was not enough evidence in participants' accounts to substantiate even tentative links by myself. This apparent lack of a relationship between participants' emotional reactions to the CB and their behavioural responses appears consistent with the aforementioned need to hide or conceal emotions, that some participants acknowledged. Fleur alludes to this when she describes how, in the face of written guidelines, there is no room for carers' personal opinions to affect their interactions with clients (although she uses the phrase 'personal opinion' rather than emotions or feelings)

"In the end these are the guidelines that nine times out of ten work, and this is what people...this is what we follow, and it doesn't matter what your personal opinion is, 'cause we're not here for personal opinion" (Fleur)

To summarise the theme of reactive strategies, participants tended initially to be concerned with managing risk. To the extent that this risk assessment had to be done

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5 The people with learning disabilities whose behaviours are alluded to by participants have had their names changed to protect their anonymity.
both effectively and extremely quickly, it could be tentatively suggested that such ‘on the spot’ risk assessment would be stressful for some participants (however none explicitly noted this). After initial risk assessment, participants were concerned with calming the client (either through ‘talking them down’, distracting them or giving them time and space to calm down on their own).

**Barriers**

Participants were generally satisfied with the way in which they had responded to the specific incident of CB that they had chosen to describe. Therefore, most did not need to identify specific factors that had prevented them from responding according to recommended interventions. Instead, they spoke more generally about potential barriers that might hinder the implementation of interventions. Some participants, like Ashton, predicted that they would feel embarrassed about implementing a reactive physical intervention to prevent a client from exhibiting challenging behaviour in the community.

"...what if I had to use SCIP....ahh I use a wrap (technique of physical intervention taught as a reactive strategy on the SCIP training course) on one of the clients. Because I know that...well I don't know, I'm assuming that the majority of the public see this client group as children, so immediately in their head we are doing that to a child. They don't realise that this person may have the, the...for want of a better word mentality of a child but he's got the strength of an adult, so you've got to stop him from, maybe even attacking them, so you use the SCIP ahh, and then....yeh I'd probably get embarrassed." (Ashton). The embarrassment that Ashton predicted he would feel appeared to arise from his perceptions about how members of the public might negatively evaluate his actions based on their own misguided beliefs about the person with the learning disability.

Another potential barrier that some participants mentioned was shortage of staff. Leroy thought that the incident of CB that he witnessed would not have occurred had there been more staff around at the time “We're supposed to have a minimum of two staff, and I'd have pushed a lot harder to get another member of staff here, 'cause it possibly, well probably wouldn't have happened if there was two members of staff”
(Leroy). Other participants echoed the need for more staff to prevent challenging behaviours from arising "Staff levels, staff levels every time" (Allegra).

In addition to embarrassment at having to implement reactive interventions in the community, and staff shortages, participants were concerned that delays in the formal training of staff (i.e. attendance on a SCIP course held at the CLDT base) could potentially act as a barrier, preventing the proper implementation of interventions. For example Leroy had not received any formal training at the time that he had to intervene to stop one client from being very physically aggressive towards another client, which meant that he relied on a trial and error approach "I don’t know, I think um, if you’re not trained properly so you don’t know how to go into the situation properly, and you know, I didn’t really know how I was meant to do it by the book, so I was sort of making it up as I go along, and I think that can be, be a problem" (Leroy). As will be seen below, participants regarded formal training as an important source of knowledge and support.

Summary of second superordinate theme – Attempting to Intervene
Participants engaged in reactive strategies to stop clients’ CB. These included removing the client from the room, distracting them or talking to them in an effort to calm them. Participants highlighted the need for immediate risk assessment and it is tentatively suggested that this hitherto unrecognised factor could further contribute to an already stressful situation. Participants did not relate their emotional reactions to the CB, and this could be due to suppression of emotions in order to maintain a ‘professional’ approach.

Superordinate Theme 3 - Sources of Support

Formal Training and Written Guidelines
All the participants were asked how and where they first learned the knowledge that enabled them to respond when they witnessed the incident of challenging behaviour that they had chosen to describe. Some participants spoke about the importance of written guidelines and formal training courses. For example Allegra acknowledged the importance of written guidelines for consolidating knowledge and said that formal training courses were important in building self-confidence.
“...but unless you’ve actually got things clearly written...a lot of it can just go in, in and out, you need that reinforcement, and you also need that um self-confidence that the SCIP courses and others like them give you” (Allegra).

Fleur thought that formal training courses were especially helpful for new staff, since they helped to increase understanding of why people with LD sometimes exhibit challenging behaviours.

“I think they’re helpful to the newer members of staff I think its sort of like they understand where the behaviours are coming from, why they think like they think or why you get that reaction to certain situations...” (Fleur)

Although several participants said that formal training courses were helpful, other participants, like Ophelia and Darius expressed reservations about how applicable training in physical techniques is to real-life situations.

“...When you physically like trying to move them from one place to another to me it doesn’t work when you’re small and you’ve got a person who’s taller and wider than you, you’ve got no chance” (Ophelia)

“Um, yeh it has been helpful, but sometimes its easy to say do this, but going back when something does happen, you know its like we were shown some of the, like arm movements, but you know, I wouldn’t have thought that in every situation you’d be able to do it exactly that way if you know what I mean...” (Darius)

Darius seemed concerned about his ability to implement the physical intervention in the recommended way, in the way taught by professionals who run the training course, when the actual CB occurred in the real-life setting. Allegra went a step further when she admitted her fear of hurting the client when she implemented a physical intervention “That is your biggest fear you know, when you’re escorting somebody ‘Am I hurting them doing this?’ (Allegra)
It is tentatively suggested that participants were aware of the potential for abusing clients when they implement a physical intervention to manage challenging behaviour. As stated explicitly by Allegra, fear of abusing the client may underpin participants' concern about implementing interventions in the same way that they were taught in the classroom setting. This interpretation would be consistent with the findings of Hawkins et al. (2005) mentioned in the introduction. In common with the participants in this study, participants in their qualitative study reported feeling emotions such as fear and self-doubt during implementation of physical interventions, and they too emphasised their concern about following the correct procedures when they implemented these interventions.

Informal Contact with Colleagues

Several participants spoke about the importance of simply talking to their work colleagues. There was a sense in which this informal support was more highly valued than formal training, and participants like Allegra explicitly mentioned this “All the support's been important but the most has been with the girls you work with” (Allegra). For Leroy, colleagues were an important source of information when he hadn't yet completed his formal training “I wasn't actually training properly at the time, I'd literally only been here four or five weeks at the time, so it was literally word of mouth” (Leroy). Participants also seemed to gain emotional support from their colleagues. For Allegra, informal contact with colleagues was important in guarding against a sense of isolation, or individual care staff wrongly believing that the challenging behaviour only ever ‘happens to them’. “…and then when you get them (the staff team) all together and then on their own and then talk to me how you really feel and then the fears start coming out and then they found they wasn’t alone” (Allegra)

Although most participants acknowledged the positive aspects of informal contact with colleagues, Ashton spoke of a negative aspect, scare-mongering with new staff
"I also think to be perfectly honest the staff member I was with didn't help matters. We were sitting in the cinema (away from the client as was his preference) and this staff member had been reminiscing stories of what he's done and what he hasn't done. I don't know whether these are true, or whether they are trying to frighten me or whatever, so I think this is all going on in my head as well" (Ashton)

**Hands-On Experience**

Participants felt that simply being in the house and getting to know the clients as individuals was extremely important. There was a sense in which this 'hands-on' experience was regarded as the most effective way to gain the necessary knowledge required to work effectively with the clients "I learn what I like from being with them....that's the most helpful" (Brent). Participants conveyed a possible reason for the overriding importance of this type of experience – only direct experience of the clients enabled them to get a sense of the clients as individuals, including the discovery of what clients would and would not tolerate.

"You just learn, getting to know your client, their likes and dislikes and um, what they tolerate" (Allegra)

"Again its knowing him, its experience of working with him, its, you know how far you can take it" (Fleur)

Day-to-day contact with the clients appeared to lead participants to habituate to the CB, so that initially intense emotional reactions that they had experienced upon first witnessing the CB became dulled after repeated exposure to the CB.

"I think I've worked in learning disabilities for such a long time that it doesn't really affect me too much at all" (Fleur)

"I was okay..um...because it was nothing new" (Allegra)
This is of course the converse situation to the fear that some participants reported experiencing upon witnessing the CB for the first time, as Darius explained:

"...But I wasn't wary about him shouting 'cause that just doesn't...doesn't bother me at all. It's just what they were going to do while they were shouting. But once they've done it once next time it happens its like 'here we go again!' (laughs) So once it had happened the first time it was fine" (Darius)

Summary of third superordinate theme – Sources of Knowledge and Support
Participants identified three different sources of knowledge and support, training courses and written guidelines, informal contact with colleagues and hands-on experience with the clients themselves. It is tentatively suggested that all three could potentially serve to bolster participants in the face of the CB, by making them more 'emotionally robust'. Participants mentioned the potential emotional benefits of all three sources, for example training courses and written guidelines to increase self-confidence, informal contact with colleagues to reduce feelings of isolation and direct experience with clients to attenuate the intensity of negative emotional reactions to the CB.
DISCUSSION

Overview
Three superordinate themes were identified – Understanding of Challenging Behaviour, Attempting to Intervene and Sources of Knowledge and Support. First, each superordinate theme will be considered in turn in the light of existing research findings. Then, methodological issues will be addressed. Finally, clinical implications and suggestions for future research will be considered.

Findings in the light of existing research

Understanding of Challenging Behaviour
A split was observed in the sample between those whose conceptualisations of challenging behaviours were consistent with definitions given in the published literature (e.g. Emerson, 1995), and those whose conceptualisations were more idiosyncratic and bore less in common with published definitions. The authors of these published definitions (Emerson, 2001) and of existing studies investigating care staffs’ understanding of what constitutes challenging behaviours (e.g. Lowe & Felce, 1995) have openly admitted that “Challenging behaviour is inevitably a socially constructed category open to subjective interpretation” (Lowe & Felce, 1995, p118). Given that what constitutes challenging behaviour is culturally determined, and given that culture could be seen to exist on a micro as well as a macro level, a case could be made for even seemingly idiosyncratic definitions from individual carers being culturally determined by the environment of the residential home in which they work.

This study has revealed that carers view informal contact with colleagues as an important source of support. It is highly probable, therefore, that care staff working within a particular home share their ideas about what is and is not challenging behaviour, as well as what causes the CB of particular clients and how to work most effectively with those clients. Hence the prevailing culture of the home both shapes and is shaped by those working within it. The point that is being made is that it is not a question of whose definition is more legitimate – the widely accepted one held within the published literature or the idiosyncratic one held by an individual carer, as
they are all in a sense valid. The pertinent issue here is the practical implication of individual carers defining challenging behaviour differently to the external consultants (clinical psychologists or other MDT members) who work into these homes, and are responsible for the design of PBS based interventions to reduce the incidence of challenging behaviours. This issue will be returned to later, in the section entitled ‘Clinical Implications’.

Most participants explained the cause of the challenging behaviour that they had witnessed in terms of both ‘internal’ and ‘external’ factors and an interaction between them. That is to say that they understood the cause of the client’s CB both in terms of the client’s individual personality and what was happening in the environment at the time. The explanation of two participants (Allegra & Fleur) in particular were sophisticated in that they incorporated the client’s previous life experiences and beliefs based on these, their individual personality characteristics and personal preferences, current physical status and how these interacted with events in the current environment to produce and maintain the challenging behaviours. As such, the causal explanations articulated by these carers appeared akin to complex psychological formulations explaining the production and maintenance of the challenging behaviour.

It seems unhelpfully reductionist to collapse these elaborate explanations to categories such as internal or external, stable or unstable and controllable or uncontrollable as is demanded by Weiner’s model or by any quantitative test of its rigour. To do so would appear to require at least simplification of carers’ explanations and at the most the loss of crucial information that conveys the essence of carers’ understandings.

However some participants’ explanations could more clearly be categorised as involving factors internal to the client that they perceived as under the client’s control (e.g. Brent & Leroy). Typically, these explanations were restricted in terms of the range of factors that were taken into account in order to explain the client’s CB. These more restricted causal explanations could be categorised according to the dimensions proposed by Weiner (1980) without risking oversimplification. For the most part, however, participants’ explanations of the cause of the CB that they had witnessed were complex and incorporated details of how factors interacted to produce
and maintain the CB. These subtle interactions may be difficult to capture using predefined quantitative measures.

The emotional reactions that participants reported were generally consistent with the findings of previous research studies (Mitchell & Hastings, 1998; Bromley & Emerson, 1995). Participants reported a range of negative emotions in response to witnessing challenging behaviours, including frustration, fear and sadness. The range of emotions reported by participants lends weight to Jones & Hastings (2003) criticism of Weiner’s model, namely that carers’ emotional reactions cannot be collapsed into one of two alternatives – either anger or sympathy.

However, participants who had previously attributed the CB to the client’s personality and who perceived the client as being in control of their behaviour, also described feeling anger and frustration in response to the CB. For example one participant (Brent) said that he felt frustrated with a client when he attributed his challenging behaviour to deliberate intent. This was consistent with the predicted relationship between internal, controllable causal attributions and the experience of anger predicted by Weiner’s model. Generally however, participants did not explicitly link their emotional reactions to the CB to their explanations of the cause of the CB.

Instead, four participants (Ashton, Conrad, Darius and Allegra) explicitly attributed their emotional reactions to their lack of experience with the client in question. This finding is consistent with previous research suggesting a relationship between the intensity of emotional reactions and the length of time that carers have worked in the field (Hastings et al. 2003).

Interestingly, three of the four participants who made this link were males talking about their experience of fear. It could be that their gender is influencing their judgement of the acceptability of fear as an emotional reaction to CB. On the other hand, at a later stage in the analysis (within the third superordinate theme) participants’ accounts also suggested that repetitive experience of the CB had the effect of dulling their emotional reactions, lending support to the contention that participants’ fear is genuinely related to the extent of their experience with the client.
It was tentatively suggested in the analysis section that participants feel fear in response to the CB simply because the CB is a frightening act and will be however many times it is witnessed. It was also tentatively suggested that the participants who spoke about fear – being male, may have felt compelled to justify their fear by attributing it to lack of experience with the client. However, with participants reporting the converse relationship (i.e. that repetitive exposure to the client’s CB leads to a dulling of emotional response) this contention appears to no longer hold.

Three participants talked about a need to conceal their emotions or deny them, and this seemed particularly the case when anger was felt (e.g. Leroy & Conrad). Although not explicitly addressed in the interview, concealment and denial of emotional reactions in response to CB could be regarded as types of coping strategy. If this were the case, then we might expect, on the basis of Hastings (2002) model of staff stress and burnout and related research findings (Mitchell & Hastings 2001; Rose et al. 2004) to find that those participants who reported such ‘coping strategies’ would also experience greater degrees of emotional exhaustion. In this investigation these factors were not found to be linked. Two participants (Ophelia & Allegra) reported feeling exhausted as a result of the CB, neither of whom had said that they denied or attempted to conceal their emotions. Rather, they linked their feelings of exhaustion to a desperate attempt to make sense of the CB. This desperate attempt to make sense was related to the elusive nature of triggers, and appeared to entail a process of mentally going over the incident, with accompanying uncertainty and doubt about their ability to intervene and their possible contribution to the escalation of the CB. To the extent that the exhaustion that participants spoke of could be regarded as symptomatic of stress (and even burnout), the findings are at least partly consistent with Hastings’ model. It is probable that trying to make sense of the incident (even after their shift has ended and they have gone home) and being unable to come up with any answers, is a stressful process for participants. Therefore the findings of this study lend weight to Hastings’ contention that staff stress levels are important to consider in relation to challenging behaviour. Furthermore, the findings serve to illuminate the mechanisms that might contribute to this stress, including a desperate attempt to make sense of the situation, and concealment and denial of emotions.
Attempting to Intervene

Participants described how they responded to the specific incident of CB that they had described. There was little evidence in the data to suggest that participants’ responses to the CB were in any way related to the emotions that they had reported experiencing. There was no evidence to suggest that those participants who had reported feeling angry or frustrated with the client subsequently attempted to avoid the client, as Weiner’s model would predict. Rather, participants attempted to reduce the risk to the client, other clients or themselves, remove the client from the immediate vicinity, and give the client time and space to calm down. In addition to not explicitly linking their behavioural responses to their emotions, participants also failed to explicitly relate their behavioural responses to their explanations regarding the cause of the CB, so again, support for Weiner’s model is lacking.

A number of potential barriers to implementation of PBS strategies and interventions have been considered in the existing research literature. Most research appears to have been devoted to the potential barriers created by care staffs’ attributions of cause, their emotional reactions to the CB and behavioural responses, and, as already discussed, has been largely focused around Weiner’s model. However other potential barriers that have been considered include a lack of provision of training in PBS strategies (Allen et al. 2005), lack of financial resources (Allen et al. 2005; Baker & Shepard, 2005), lack of knowledge of behavioural approaches (Oliver et al. 1996) and carers’ lay beliefs that conflict with the notions of PBS (Baker & Shepard, 2005).

Although participants’ accounts provided evidence that this sample are practising PBS strategies as part of their daily contact with clients, they also explicitly highlighted, or alluded to, a number of existing or potential barriers that can act as obstacles to implementing the recommended strategies. For example two participants (Allegra & Leroy) highlighted the need for more staff. To the extent that the number of staff employed by an organisation is limited by financial constraints, this is consistent with previous literature citing financial constraints as a potential barrier to implementation of the PBS approach (e.g. Allen et al. 2005; Baker & Shepard, 2005).
The same two participants also mentioned problems with delays between taking up a position as a support worker and receiving formal training in the PBS approach. These participants are in fact relatively fortunate in that they do have a PBS training course in their locality and every effort is made to allow new support workers to receive the training as soon as possible. However, places on the training course are still limited and although the training is based on a rolling programme (see Baker & Shepard, 2005) to enable as many staff to attend as possible, there are obviously still difficulties with making sure that all new staff receive training almost as soon as they commence employment. It can only be assumed that delays in or absence of formal training presents an even more serious problem in regions that lack such formal training provision.

Sources of Knowledge & Support
Generally participants reported that they found the formal training in PBS that they had received, and any written guidelines that they had received from CLDT members, helpful. For example one participant (Allegra) emphasised how the courses were good for building the confidence of staff.

However three participants were sceptical about the transferability of physical reactive strategies to real life settings. One participant explicitly spoke of her fear of hurting the client when she implemented a physical intervention. It is tentatively suggested that participants' concern with the transferability of physical interventions from the classroom to real life settings is underpinned by an awareness of the potential for abusing the client and a concern that implementing the interventions incorrectly could result in the occurrence of an abusive practice. Evidence supporting such a contention is provided by the findings of Hawkins et al. (2005). As part of their study, participants were interviewed about their feelings before, during and after the implementation of a physical intervention. Fear and self-doubt were among the emotions reported as having been experienced during implementation of the intervention, and participants also emphasised a concern for implementing the technique in the correct way.
The most important source of support and knowledge seemed to be experience within the workplace environment, both through contact with colleagues and actual direct ‘hands-on’ experience with the clients themselves. The finding that informal support from colleagues was highly valued by participants is not unexpected as it has been noted in the existing literature (e.g. Hastings 1995). A possible reason for this is that informal support from colleagues seems to serve as a protective factor against work-related stress (e.g. Harris & Thomson, 1993; Hatton & Emerson, 1993). One participant, Allegra, provided evidence for this when she suggested that support from colleagues helped to prevent individual support workers from feeling isolated in the face of the CB.

The findings suggested that participants found the greatest source of knowledge to be direct, or ‘hands-on’ experience with the clients themselves. Interestingly, there was a sense in which informal contact with colleagues was identified as a more important source of knowledge and support than formal training and written guidelines. This may be because colleagues can provide emotional support as well as technical expertise, suggesting that emotional support is very important in this work.

The general finding in the existing literature (e.g. Hastings, 1995) and in this investigation, namely that participants appear to value informal support from colleagues within their staff team more highly than formal training, has important implications for the way in which the PBS approach and related strategies are disseminated. Currently, the dominant way of disseminating information about the PBS approach is through the use of formal training, such as through the SCIP course. A new, revised model for formal training in the PBS approach have also been recently published (Dench, 2005). However, the findings of this study and others suggest that formal training programmes may not be the most effective way of passing on the required information. This will be discussed further in the section entitled ‘Clinical Implications’.

Five participants said that direct, ‘hands-on’ experience with the clients had been important in enabling them to gain the knowledge required to implement interventions. It was interesting to find that two participants explicitly mentioned the
effect that repetitive challenging behaviours had on dulling the intensity of their emotions. This is consistent with Hastings (1995) finding that carers’ emotions became ‘numbed’ over time.

Figure 1 depicts the themes identified in this study in diagrammatic form, together with tentative relationships between themes that have been suggested in participants’ accounts or interpreted by myself, the researcher. I have tentatively suggested that a number of factors highlighted by participants could potentially contribute to the ‘stress’ that Hastings (2002) proposes in his model. Perhaps most important is the finding that participants experience triggers as elusive and how this leads to a process of desperately trying to make sense of the situation, which participants reported experiencing as exhausting.

**Influence of Gender – Still a Neglected Topic?**

Interestingly, none of the participants mentioned the influence of gender spontaneously whilst explaining their understanding of the cause of the incident of challenging behaviour that they witnessed, or in covering the other issues covered in the interview schedule prior to the section about gender. When they were explicitly asked about the influence of gender, participants seemed to find it difficult to formulate responses to the questions that demanded them to think about the impact of their client’s gender or their own gender. For example when asked whether she felt her gender had an impact on the way in which she understood the client’s challenging behaviour, Ophelia said that yes, it did have an influence. However when asked in what way her gender influenced her understanding, she replied “...I don’t know because male and female they think slightly different from...one another......at this present moment I can’t......” This suggests that such questions might have been too abstract and hypothetical for participants to answer immediately, but also suggests that participants may not think about the impact of gender in their everyday work with clients.
Figure 1: Diagram to show superordinate themes, themes and hypothesised relationships between the themes based on the findings of the study. Solid line arrows depict relationships evidenced in the data; dashed line arrows depict tentative links suggested by the researcher.

Understanding of CB

What Constitutes CB

Understanding of Cause

linked – if client held resp. then anger felt

Emotional Reactions

Perceived Elusiveness of Triggers

Emotional Exhaustion/Stress

Sources of Knowledge & Support

Formal Training & Written Guidelines
(But concerns re transferability of physical interventions)

Informal Contact with Colleagues

Hands-On Experience

Attempting to Intervene

Reactive Strategies

e.g. - On-the-spot risk assessment

Barriers

e.g. - Not enough training
- Not enough staff
- Embarrassment re negative evaluation by public in community

Not linked partly due to process of concealment and denial of emotions
Clements et al. (1995) proposed that if carers ignore the impact of gender on clients then they may fail to understand how the different needs of either gender are manifested in their challenging behaviour. Only three participants felt that clients' gender influenced their challenging behaviours, which suggests that the majority of participants in this sample were unaware of the possible influence of gender on the challenging behaviours of their clients. This suggests that ideas about gender and how this may affect the manifestation of challenging behaviour should perhaps be incorporated into existing training programmes on PBS. This will be considered further in the section entitled 'Clinical Implications'.

Methodological Issues

Design
IPA was employed in this investigation. This qualitative method does have some limitations, two of which will be considered here (the interested reader is advised to consult Willig, 2001 for a fuller discussion). The first criticism concerns the role given to language. IPA conceptualises language as a vehicle that the participant uses to express experience and no more. However strict social constructionists would argue that language constructs experience rather than merely expressing it. IPA can be criticised for not acknowledging the possible role played by the participants' language in constructing their experience (Willig, 2001)

The second criticism concerns the accounts given by the participants. The medium upon which the analytical process is based is the participant's language. Since the aim of IPA is to capture something of the experience of the phenomena under study from the perspective of the participant, IPA assumes that the language that the participant adopts to express their experience is an accurate reflection of the experience itself. However it could be argued that some participants are not able to articulate their experiences in the sophisticated way that this method demands (Willig, 2001), and therefore some potential participants may not be suitable candidates for the semi-structured interview. Thus the researcher may need to deny themselves the opportunity of access to some potential participants' rich and unique experiences simply because the participants themselves are unable to express their experiences in a sophisticated enough way.
Participants

Recruitment problems

No support workers from one home approached expressed an interest in the study. Only two from another home expressed an interest and one of these later failed to forward the researcher her contact details. This low uptake necessitated having to recruit Home Managers to participate in the study. One Home Manager attributed the apparent lack of interest shown by the support workers in her home to painful emotions. She explained that one of the residents who had exhibited severe challenging behaviours had recently been taken out of the home and placed in a different home. She said that the support workers were feeling very raw and thought that the interview would be too painful a process at that time. Consistent with the findings of this report, this serves as another illustration of the powerful emotions that challenging behaviours elicit in carers. It also suggests that carers’ powerful emotions linger even after the client in question has moved on.

Strengths & Weaknesses of Sample

The sample has a number of strengths. First, there were ten participants, which is the recommended number for IPA (Smith et al. 1999). Second, there were both males and females included in the sample, which enabled the perspectives of both genders to be elicited – considered particularly important in relation to the questions on the impact of gender in the interview schedule. Third, although the ethnic origin of most participants was white British, one participant was of Asian-European origin and one participant was of Indian origin, therefore the sample contained a mixture of ethnicities. This perhaps suggests the findings are of relevance to a broader spectrum of carers rather than just those who are white British. Fourth, the extent of participants’ experiences varied. This was evident in the richness of participants’ accounts as evidenced by the sheer length of the interview transcripts – those participants who had worked in the field the longest tended to talk at the most length about the issues raised in the interview schedule.

One possible limitation of the sample is the inclusion of three Home Managers. This meant that the sample was not homogenous in terms of the positions occupied by the
participants. Rather, the Home Managers occupied positions of seniority relative to the support workers. However, the crucial element that all participants had to share was experience in the daily care of people with learning disabilities and challenging behaviours (including exposure to a specific incident of challenging behaviour). The sample was homogenous to the extent that they all shared experience of this phenomenon. In addition, three of the four female participants were Home Managers whereas all male participants were support workers. This split came about largely because the two homes where there was poor uptake were all-female (female residents and female staff), whereas the home where a lot of interest was shown was nearly all male (with the exception of the female manager). It is interesting to reflect on why the male support workers appeared to show more interest in the study than the female support workers, since traditional gender stereotypes would suggest that men would perhaps be less likely than women to offer to participate in a study that involved talking about their thoughts and feelings. Such traditional gender stereotypes may not hold much relevance in situations where, as Fleur suggests, a degree of sensitivity and being ‘in touch with one’s feelings’ is a necessary prerequisite for working in the field:

"... 'cause I think if a male comes into this environment he's got to be fairly caring and a sensitive person to want to do this job......................especially from a male point of view, knowing that your going to have to do a bit more personal care and it is more...feminine side of one's character shall we say...." (Fleur)

Issues of gender aside, there are a number of other possible explanations for this split having arisen with this sample, between females in the sample occupying managerial roles and males occupying support worker roles. For example, in the invitation letters and information sheets sent to Home managers I introduced myself as having spent a six month placement working within the CLDT, and stated that one of my supervisors was a member of this team. It could have been that the staff in the two homes where little interest was shown, had less positive relationships with the CLDT, and were therefore less keen to become involved in research that may have been perceived as being ‘commissioned’ by the CLDT. Ironically, such ‘reluctant’ staff would probably, if interviewed, provide the richest and most enlightening accounts with regard to the
issues set out in the introduction (i.e. why PBS-led interventions are not always implemented in the way intended by those that designed them). Another possible explanation for the male/female split with regard to hierarchical position within the sample relates to the power the Home managers held with regard to accessing support workers. I had to go through them to gain access to the support workers, therefore Home managers could have (intentionally or unintentionally) facilitated or obstructed my access to these potential participants. It may simply have been that the Home manager of the male home from which most of the participants were recruited was more proactive in advertising the research to her support workers.

**Interview**

*Acceptability of Interview questions*

As the stage of data collection progressed, I kept notes in a reflective diary regarding some interesting effects that I was observing. These effects appeared to be related to asking participants to recall and describe specific incidents of challenging behaviour that they had witnessed. I had regarded the fact that the interviews were based on real life incidents of CB that participants had witnessed as one of the major strengths of the study. However as the interviews progressed I noticed that participants were sometimes reluctant to 'claim ownership' of the experience by talking about it in the first person. Instead, they described the incident in the second or third person, or referred explicitly to what 'usually' or 'typically' happens (e.g. “Well what typically happens is…….” “You would be doing this and…….” “………….and then she would usually…….”) thus appearing to distance themselves from the specific incident. Some participants attempted to justify this tendency to recall what typically happens by saying that the CB had happened so many times that they found it difficult to recall a specific incident. It would certainly seem less effortful for participants to talk about what usually happens rather than trying to recall exactly what happened in relation to one particular incident. It would also appear to be less taxing emotionally if it is indeed the case that recalling a specific incident in detail would involve (to some degree at least) a re-igniting of the emotions felt at the time of that incident. However if it is indeed the case that talking about incidents of CB in general terms serves to buffer the carer from previously experienced emotions then this could present problems in terms of the richness of information offered, since presumably
they would not recollect the particular emotion experienced in relation to that specific incident or the intensity with which that emotion was experienced. Although this is a limitation, whether action can be taken to prevent it in the context of the interview situation is doubtful — rather, a mere acknowledgement of the potential influence of this factor may have to suffice.

For the most part, the questions contained within the interview schedule appeared to have been crafted sufficiently sensitively so as to elicit participants’ own perspectives.

**Impact of Researcher on Interview and Findings**

Both my supervisors and I had, in the initial stages of planning the research, recognised the potential for participants to disclose abusive practices during the course of the interview. We also recognised that a) it would be unethical not to report such disclosures of abuse to the appropriate authorities b) it would be unethical not to warn potential participants of this in the information sheet. This effectively created a power imbalance between participants and myself in the context of the interview, since they knew I had the power to act should they disclose an abusive practice either committed by themselves or others.

Linked to this, I was aware at times that participants may have been giving me the information that they thought I wanted to hear (‘socially desirable’ responses) rather than their honest opinions. This may have been partly because of the issue noted above, and also simply because of my connections with the CLDT (although I also attempted to make clear to participants that i) with the exception of disclosure of abusive practices, participants’ identities would remain anonymous — this included anonymity with regard to the CLDT ii) I was not an active member of the CLDT and as such I did not have knowledge of the clients or of the particulars of the CLDT’s input to the home.

During the interviews I often found myself grappling with the issue of whether to come away from the interview schedule in order to follow up on unanticipated aspects of experience expressed by the participants. If time was taken to explore such unanticipated aspects further, then this may have meant that other areas of the
interview schedule could not be covered in the time available. As the interviews progressed I began to get more of a feel for what was unanticipated, and yet central to the phenomena and worthy of further exploration, and what was unanticipated but peripheral to the topic of investigation. In the event of the latter I found myself struggling with another issue – how to let the participant know that they had been heard, and yet still retain enough control over the interview process to cover the areas I had set out to cover. I realise that I was uncomfortable with the power being weighted in my favour. Upon reflection, I realise that some participants may have been uncomfortable with this too, and maybe the tendency of some participants to answer questions before I had finished asking them, or persisting with a particular topic despite my attempts to move the conversation on, were actually attempts to take back some of the power that they perceived me to hold.

As the interviews progressed I often found myself reflecting, both during and after the interviews, about participants' ideas regarding what constitutes CB and how they differed from my own. During the first few interviews, I was aware of a strong urge to try and get the participant to produce what I considered to be a 'good enough' example of CB. This urge was borne out of a realisation that some participants' ideas about what constitutes CB did not appear to match the definitions that I had come across in the literature (or, more accurately, did not match my interpretation of those definitions), and the anxiety that I felt when this realisation dawned. Further reflection led to the conclusion that if participants' ideas about what constitutes CB did appear to differ from the definitions given in the literature, then this was an important finding in itself. Therefore I went with their ideas and guarded against imposing my own. I hope that I have been successful in the analysis and discussion sections of this report, in drawing the reader's attention not to a debate about whose definition is 'correct', but rather to the finding that differences exist in the way that CB is conceptualised, and that these differences may have important clinical implications.

A final point concerns the potential impact of my gender on the interview process. As the interviews progressed I became increasingly aware that participants did not seem very forthcoming when it came to describing their emotional reactions to the incident.
of CB they had described. This awareness may have stemmed from my knowledge of existing literature and the relative proliferation of examples of emotional reactions identified by previous researchers. I noticed that the majority of respondents in the study conducted by Rose et al. (2004) were female whereas the majority of participants in my study were male. This led me to draw yet again on a male gender stereotype that suggested that men are typically less comfortable about expressing their emotions than are women. I wondered whether my being female made it easier or more difficult for these male participants to talk about their feelings. It would be interesting to examine the effects of congruence between the gender of the interviewer and interviewee on the richness of information elicited during the interview.

Clinical Implications and Suggestions for Future Research
Several clinical implications can be drawn from the findings of this research. First, participants reported finding trigger events – things that should serve to alert them to the probable onset of CB and signal the need for early intervention - difficult to identify and this was associated with exhaustion and other negative emotions. This finding would not have been anticipated. Existing formal training courses attempt to drive home the message that there is always a trigger, and the challenge to care staff is to identify it early enough to intervene to prevent escalation of the CB. External consultants working into services for people with LD and CB, and PBS course trainers, may need to acknowledge the possible negative effects of such a ‘definite’ message – i.e. that care staff may be exceptionally hard on themselves if they fail to identify triggers, and this may ultimately be detrimental to their emotional wellbeing.

Second, the finding that some participants’ conceptualisations of what CB constitutes appeared quite different from definitions of CB that appear in the published literature and are espoused by the external consultants charged with the responsibility of designing interventions. This could have important implications for the implementation of interventions if, for example, behaviour to which the intervention is targeted is not the behaviour that the individual carer defines as challenging. In such a case, it could reasonably be assumed that the carer’s motivation to implement the recommended intervention may be lowered by their doubts about its relevance. There may be a need for open discussion from the outset between external consultants and
care staff so that a consensus can be reached about what should be defined as challenging behaviour, before such disagreements arise.

Third, the finding that participants were concerned about the transferability of physical intervention techniques taught on formal courses to the real-life setting. It is suggested that this is underpinned by an awareness of the potential for abuse of clients. Perhaps this concern should be more explicitly acknowledged and validated when the techniques are taught. Trainers could perhaps be more clear about at what point a physical intervention could clearly be categorised as abusive – although there may be ethical constraints to this. Also, it may be possible to teach physical interventions in a more natural, community setting rather than the classroom, to increase carers’ confidence about their ability to appropriately intervene in the real-life setting, although this would be likely to demand increased time and resources.

Fourth, the finding that the influence of gender had often not been considered by participants prior to the interview. This suggests that they are largely unaware of how the client’s gender may influence a) how their CB is manifested, or b) the way in which they respond to the client. To the extent that care staff may unintentionally draw upon gender stereotypes in order to explain and respond to CB, course trainers and external consultants may need to open up discussion on this topic in order to increase care staffs’ awareness of its potential influence.

This study has highlighted a number of factors that could potentially contribute to stress in care staff, including hitherto unanticipated factors such as the elusive nature of trigger events. Future research should aim to further explore these factors and how they might contribute to stress in care staff. Future research might also aim to further examine the protective effects of other factors identified in this study, such as the effects of formal training on self-confidence and direct, hands-on experience with CB on attenuating intense negative emotional reactions.

The findings of this study have served to illuminate the complexity of some carers’ explanations of the cause of the client’s CB. Future researchers should be cautious in attempting to confine participants’ explanations of cause to predefined dimensions lest
they miss out on the essential essence of the participants’ understanding or miss the
opportunity to identify previously unanticipated factors.

Finally, perhaps future research studies need to draw more of a distinction between
proactive interventions, that serve to prevent the occurrence of CB by equipping the
person with new skills, versus reactive interventions that must be implemented when
CB is exhibited. Whilst asking participants about specific incidents of CB that they
have witnessed enables us to learn about how they experience the CB and how this
influences their response, it also restricts us to finding out about their reactive
response, rather than their implementation of proactive interventions. However, it is
the proactive interventions that should be most effective in reducing the CB in the
long-term. Therefore, in addition to continuing to examine how care staff experience
CB, it would also seem essential for future research to carers’ experiences of
implementing proactive intervention strategies in order to identify potential
difficulties at this earlier stage in the intervention process.
REFERENCES


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Appendix 1
Letter of Approval for Local Research Ethics Committee
Brighton and Mid Sussex Research Ethics Committee
East Sussex Research Ethics Committee

26 October 2004

Dr Hayley Pringle
Trainee Clinical Psychologist
Dept. of Psychology,
School of Human Sciences,
University of Surrey,
Guildford, Surrey
GU2 7XH

Dear Dr Pringle,

Full title of study: Attributions, emotions and behavioural response: A qualitative study of professional carers of people with severe learning disabilities and challenging behaviour.

REC reference number: 04/Q1905/43

Ethical opinion

Thank you for your email of 31 August 04 and 21 October responding to the Committee’s request for further information on the above research and submitting revised documentation.

The Chairman has considered the further information on behalf of the Committee and I am pleased to confirm a favourable ethical opinion has been given.

The favourable opinion applies to the following research site:

Site: Hastings & Rother Community Learning Disabilities or at professional carers’ place of work.

Principal Investigator: Hayley Pringle *

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document Type: Application
Version: 2 with part C included
Dated: 28/06/2004
Date Received: 30/06/2004

Document Type: Investigator CV
Version: 1

An advisory committee to Surrey and Sussex Strategic Health Authority
Management approval

The study may not commence until final management approval has been confirmed by the organisation hosting the research.

All researchers and research collaborators who will be participating in the research must obtain management approval from the relevant host organisation before commencing any research procedures. Where a substantive contract is not held with the host organisation, it may be necessary for an honorary contract to be issued before approval for the research can be given.

Notification of other bodies
We shall notify the research sponsor that the study has a favourable ethical opinion.

Statement of compliance (from 1 May 2004)

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

REC reference number: 04/Q1905/43 Please quote this number on all correspondence

Yours sincerely,

[Signature]

Michelle Roman
Ethics Administrator

michelle.roman@bhcpcnhs.uk
www.corec.org.uk

On behalf of the Chairman

Enclosures  Standard approval conditions
Appendix 2

Letter of Approval from University Ethics Committee
12 November 2004

Dr Hayley Pringle
Trainee Clinical Psychologist
Department of Psychology
School of Human Sciences

Dear Dr Pringle

Attributions, emotions and behavioural response: A qualitative study of professional carers of people with severe learning disabilities and challenging behaviour (EC/2004/107/Psych) - FAST TRACK

On behalf of the Ethics Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the submitted protocol and supporting documentation.

Date of confirmation of ethical opinion: 12 November 2004

The list of documents reviewed and approved by the Committee under its Fast Track procedure is as follows:-

Document Type: Application
Version: 1
Dated: 02/11/04
Received: 04/11/04

Document Type: Insurance Proforma
Version: 1
Received: 04/11/04

Document Type: Project Summary
Version: 1
Received: 04/11/04

Document Type: Appendix 1 - Detailed Research Protocol
Version: 1
Dated: 28/06/04
Received: 04/11/04

Document Type: Appendix 2 - Interview Schedule
Version: 1
Dated: 28/06/04
Received: 04/11/04
This opinion is given on the understanding that you will comply with the University's Ethical Guidelines for Teaching and Research.

The Committee should be notified of any amendments to the protocol, any adverse reactions suffered by research participants, and if the study is terminated earlier than expected with reasons.

You are asked to note that a further submission to the Ethics Committee will be required in the event that the study is not completed within five years of the above date.

Please inform me when the research has been completed.

Yours sincerely

Catherine Ashbee (Mrs)
Secretary, University Ethics Committee
Registry

cc: Professor T Desombre, Chairman, Ethics Committee
   Dr P Tibbles, Supervisor, Psychology
   Dr P Baker, Field Supervisor
Appendix 3
Letter from Research & Development
Dear Hayley,

Re: Learning disabilities and challenging behaviour: Carer's experiences.

Thank you for your phone call this morning regarding the above study.

Following our correspondence in July 2004, I would like to confirm the situations when Research Governance approval (or R&D approval) must be obtained, as set out in the Research Governance Framework for Health and Social Care (2001). Research involving any of the following must receive RG approval prior to commencement:

a) National Health Service (NHS) patients (i.e. people recruited to the study by virtue of their past or present treatment or care by any NHS organisation);
b) Tissue, blood or any other material removed from NHS patients;
c) Data collected from past or present NHS patients, including all information stored in the patient’s health records;
d) The use of NHS premises or facilities;
e) NHS staff;
f) Any other person or group to whom an NHS Organisation owes a duty of care.

In your correspondence, you confirmed that you did not require access to any of the above sources, and I therefore informed you that you did not require RG approval.

Please do not hesitate to contact me should you require any further information.

Yours sincerely,

Helen Laver
Research Governance Manager

Tel: 01903 285222 ext. 4195
Fax: 01903 285217
Email: helen.laver@wash.nhs.uk
Appendix 4
Letter to housing company management team
7th October 2004

Support & Development Manager

Dear

Re: Hayley Pringle's Research Project
“Learning disabilities and behaviour: Carer’s experiences”
Project Reference No: 04/Q1905/43

It was nice to talk to you again the other day. As promised, please find enclosed the protocol, participant information sheet and consent form for the research which I hope to carry out in partial fulfilment of the requirements for the award of a Psych D in Clinical Psychology. Although the East Sussex Local Research Ethics Committee provisionally approved of the project at their meeting on 20th July, I needed to make some amendments and am awaiting confirmation of their approval. Members of the ethics committee were concerned about the possibility of abusive practices being disclosed during the interviews. Although such an eventuality is hopefully unlikely, they did require me to be explicit about possible consequences for the participant or others if they did disclose such information. Therefore I had to include this in the participant information sheet – I hope it won’t be too off-putting for carers who may wish to act as participants!

Although I tried to summarise the research over the phone my verbal description was probably a bit brief, so I thought I’d take the opportunity to give you a written summary here. Clinical Psychologists working with people with severe learning disabilities are often involved in designing interventions that aim to prevent a person with severe learning disabilities from resorting to challenging behaviours (including self-injurious behaviour) to communicate their needs. Challenging behaviour can be defined as any culturally abnormal behaviour, which, by virtue of its duration, intensity or frequency, poses a serious threat to the physical safety of the person or others, or is likely to seriously restrict their access to community facilities (Emerson, 1995). Interventions are often aimed at meeting the person’s needs before they resort to challenging behaviour, and aim to develop the person’s ability to communicate more adaptively. Clinical Psychologists often design interventions, but their successful implementation is dependent on the co-operation of the staff involved in the daily care of people with severe learning disabilities.
However, research has shown that interventions are often not implemented consistently by care staff, with the result that challenging behaviour is at best maintained, and at worst increased. Research has been undertaken to try to find out why interventions are not implemented, and suggested contributory factors include the carer’s understanding of the cause of the challenging behaviour and their emotional responses to it.

One model that is often used to explain and predict how professional carers might respond to the challenging behaviour of people with severe learning disabilities is that proposed by Weiner (1980). The model predicts that if the carer attributes the cause of a service user’s challenging behaviour to an ‘internal’ factor (e.g. their disposition), this will lead the carer to experience negative emotion towards the service user (e.g. anger) and will increase the probability that the carer will seek to avoid the service user in future. This could lead to an increase in the client’s challenging behaviour, if its function is to communicate the service user’s desire for social contact. One potential difficulty with the model is that it was borne out of quantitative research methods. A drawback of such methods is that they use pre-existing measures with pre-defined categories to elicit information from carers about their understanding of challenging behaviour. This strategy allows the researcher to impose their own biases and forces the carer to respond in a manner that fits the pre-defined response categories contained within the measure. In addition, research offering support for Weiner’s model makes use of hypothetical situations to elicit details from carers, rather than asking them about real-life instances of challenging behaviour to which they have been exposed. The use of hypothetical vignettes may be problematic in that the method is unlikely to capture the complex and subtle nature of carer’s real-life interactions with the service users in their care.

Therefore a qualitative study is proposed, whereby semi-structured interviews will be used to gain an understanding of how professional carers experience real-life instances of challenging behaviour demonstrated by service users in their care. Interviews will be transcribed and subjected to Interpretative Phenomenological Analysis (IPA), which aims to enable the researcher to develop an ‘insider’s perspective’ (Conrad, 1987), thus allowing the researcher to remain open to aspects of the carer’s experience that she may not have anticipated.

One aim of the research will be to assess the degree of similarity between carers’ accounts, and the constructs and predictions proposed by Weiner (1980).

Another aim will be to explore carer’s understanding of gender issues and the extent to which they impact upon their understanding of challenging behaviour. Gender issues have not been considered in past research, despite carers highlighting their importance. In addition, it would seem particularly important to consider gender issues in the light of the Department of Health’s publication entitled “Mainstreaming Gender and Women’s Mental Health” (Department of Health, 2003).

A third aim will be to explore the factors that hinder professional carers’ ability to implement recommended interventions.
I aim to interview ten professional carers, and to invite them to a seminar once the interviews have been completed, so that I can present my findings and invite them to discuss the findings and possible implications. In addition, I hope to submit the final report for publication in a respected, peer reviewed journal.

If you have any queries or concerns please do not hesitate to contact me on either 01424 432546 (Home) or 07929 169927 (Mobile). If you need to contact me in writing, my address is 26 The Spinney, Hastings, East Sussex, TN34 1YE.

Best Wishes,
yours sincerely

Dr Hayley Pringle
Trainee Clinical Psychologist,
Department of Psychology,
University of Surrey.
Appendix 5
Letter to Managers of individual homes
Research exploring Professional Carers' experiences of Clients with Learning Disabilities and Challenging Behaviour

My name is Hayley Pringle and I am a third year Trainee Clinical Psychologist at the University of Surrey. During my third year, I am required to complete a research project in partial fulfilment of the requirement for a Psychology Doctorate in Clinical Psychology. During my training, I completed a six-month placement with the Hastings and Rother Community Learning Disabilities Team, with Derek Blackburn and Peter Baker.

Whilst there, I developed an interest in how Professional Carers manage incidences of challenging behaviour demonstrated by the clients in their care. As you know, the Clinical Psychologists in the Team are often involved in designing interventions to help a person with a learning disability to reduce their reliance on challenging behaviour. I became increasingly aware of how Clinical Psychologists both depend on Professional Carers to inform the design of interventions, and to implement those interventions consistently. However available research evidence and my own experiences suggested that there are sometimes problems with the implementation of guidance. There may be several reasons as to why Carers experience problems with the implementation of outside guidance. For example, this may come about as a result of disagreements about why the person engages in challenging behaviour. Indeed, one of the main findings of research is that people come to different conclusions about why someone is exhibiting challenging behaviour. However, previous research has often relied on simple questionnaires that limit opportunities for Carers to offer their perspective.

The aim of my project is to really gain a sense of the Carer’s perspective of what it is like to be involved in the care of a person with a learning disability who demonstrates challenging behaviour. I would like to interview up to ten Carers individually, to gain an understanding of their perspectives. The interview will be informal, and I hope to cover areas such as the Carer’s understanding of why the client engages in challenging behaviour, what factors hinder the implementation of recommended interventions, and whether the Carer thinks gender issues influence their response to a client’s challenging behaviour.

The research is being supervised by Peter Baker from the Hastings and Rother Community Learning Disability Team and Vicky Senior from the PsychD Clinical
Psychology Course at the University of Surrey. It has received ethical approval from East Sussex Local Research Ethics Committee.

Chris Small, Support and Development Manager at East View Housing, has given the project her full support, and has kindly provided me with the names of Managers of East View homes, one of whom is of course yourself! She has recommended that I get in touch with you to ask if you would assist me by providing the names of Professional Carers working under your management, so that I can invite them to participate in the research.

In order to be eligible to participate in the study, Carers need to be in regular contact with a client with challenging behaviour during the course of their work.

I plan to interview each Carer for about an hour, hopefully either at their place of work or in a quiet room at the CLDT base at Eversfield Place in Hastings. After I have analysed the interview data, I will hold a seminar at the CLDT base and invite both participants and other Carers along, so that I can suggest my tentative findings and provide an opportunity for Carers to contribute further to my understanding. Once I have written the final report I aim to submit it for publication, and present the findings at professional conferences.

I will phone you shortly to answer any questions that you may have. Ideally, it would be great if you could assist me in this research process by providing me with the names of potential participants. I can then send them personalised letters of invitation and information sheets. Each information sheet contains a reply slip and has an SAE attached. The reply slip enables the potential participant to say whether or not they would like to participate. It also contains an option to get in touch with me to gain more information prior to deciding whether or not to take part.

As I mentioned above, I would like to be able to interview Professional Carers either at their place of work or at the CLDT base at Eversfield Place in Hastings. The idea behind interviewing carers at their place of work is that this might be more convenient for them, but you as the Home Manager may feel that there are some constraints to this, and I would be very happy to discuss this matter with you.

Thank you for your time

Yours sincerely

Hayley Pringle
Trainee Clinical Psychologist
University of Surrey

(Supervised by Peter Baker,
Consultant Clinical Psychologist,
Hastings & Rother Community Learning Disabilities Team, &
Victoria Senior Research, Research Tutor, PsychD Clinical Psychology,
University of Surrey).
Appendix 6
Information Sheet
Research exploring the Perspective of Professional Carers:

"CARERS OF PEOPLE WITH LEARNING DISABILITIES AND CHALLENGING BEHAVIOURS: A STUDY EXPLORING THEIR IDEAS REGARDING THE REASONS FOR THE BEHAVIOURS, HOW THEY FEEL ABOUT THEM AND HOW THEY RESPOND."

My name is Hayley Pringle and I am a Trainee Clinical Psychologist based at the University of Surrey. I am currently looking for volunteers to take part in my Major Research Project, which aims to explore professional carer's views regarding a recent incident of challenging behaviour that they have witnessed and/or been involved in. My supervisors are Dr Peter Baker, Consultant Clinical Psychologist at Hastings & Rother Community Learning Disabilities Team, and Dr Victoria Senior and Dr Paul Tibbles at the University of Surrey.

The purpose of this information sheet is to inform you of a research study that may be of interest to you, and to invite you to take part. Before you decide whether or not to take part, please take time to read the information below, as it is important that you understand the purpose of the research and what it will involve.

What is the purpose of the study?
The primary purpose of the study is to explore professional carer's thoughts regarding what caused a recent incident of challenging behaviour that they witnessed, what they felt about it and what (if anything) they did and why. Additional aims of the study are to discover what makes it difficult for carers to implement intervention programmes, and whether carers think gender issues are important in how they interact with people with learning disabilities and challenging behaviour.
Who can take part?
To be eligible to take part, you need to be in regular contact with one or more people with learning disabilities and challenging behaviour in your role as a professional carer.

If I agree to take part, what is involved?
If you agree to take part, you will be asked to participate in an informal interview with myself, lasting for about an hour. The interview can take place at your place of work during your regular working hours, or at the Hastings & Rother CLDT base.

Before the interview you will be asked for your consent to have the interview audiotaped for the purpose of analysis. The audiotape will be kept in a secure location and destroyed as soon as the interview has been transcribed. Thereafter the interview transcript will be assigned a number and your identity will remain anonymous.

It is also important that you understand that if during the course of the interview you disclose information about any abusive practices (such as those that carry high risk of physical or psychological harm to the service user) I am duty-bound to report this information in line with published procedures regarding Protection of Vulnerable Adults. Therefore, I am required to discuss any such disclosure with Duty Social Workers within the CLDS Team, who would then decide whether further investigation were warranted, and what action would need to be taken. It is important that you understand that in a worst-case scenario, disclosure of an abusive practice could potentially result in the perpetrator losing their job and being prosecuted by the police.

Please note that participation in this study is entirely voluntary and you are free to withdraw your participation at any time.

What will happen to the results of the research study?
I plan to hold a meeting with all the carers who participated in the study, so that I can share my findings and carers can comment on them if they wish. The findings should help us to better understand how professional carers experience the challenging behaviour of the people that they care
for, so that better interventions can be designed or barriers that prevent interventions from being implemented can be removed. To this end, I hope to publish the findings of the study in an academic journal so that other professionals who work in the area, or interested lay people, can learn from them (please note that participant's identities will remain totally anonymous in any future publication). I also plan to present the findings at professional conferences.

If you would be willing to take part or if you have any questions or concerns, please complete the reply slip below, and return it to me in the stamped addressed envelope provided. I will then contact you at the earliest opportunity. If you decide that you would not like to take part, I would be very grateful if you could complete the reply slip accordingly and return it, so that I know that the invitation reached you.

Thank you for your time.

Hayley Pringle
Trainee Clinical Psychologist
I would be willing to participate in the research

I would like the opportunity to ask some questions prior to deciding whether or not to take part

My contact details are as follows:

Name: ..........................................................................................
Address: .....................................................................................
Tel no: ..........................................................................................

I would not be willing to take part in the research

(Please return to Hayley Pringle, Third Year Trainee, PsychD Clinical Psychology, Department of Psychology, University of Surrey, in the stamped addressed envelope provided – Thank you)
Appendix 7
Letter of Invitation
10th January 2005

Professional Carer

Dear

Re: Research exploring the perspectives of Professional Carers of people with learning disabilities and challenging behaviours

My name is Hayley Pringle and I am a Trainee Clinical Psychologist at the University of Surrey. As part of my training I am conducting a research project, supervised by Dr Peter Baker of the Hastings & Rother Community Learning Disabilities Team. The research is about Professional Carers’ experiences of the challenging behaviour that they may be exposed to during the course of their work. I am writing to you because you may be interested in taking part in my research project.

If you would like to participate in the research, it will involve an informal interview with myself, lasting about an hour, in which I will ask you about your experiences of the challenging behaviour demonstrated by people with learning disabilities in your care. The interview can be conducted at your place of work or in a room at the Community Learning Disabilities Team Headquarters at Eversfield Place, Hastings.

I have enclosed an information sheet, which describes the research in greater detail. If, after reading the information sheet, you decide you would be willing to take part, or that you would like more information prior to deciding whether or not to take part, please complete the reply slip on the last page of the information sheet and return it in the stamped addressed envelope provided. I will then contact you at the earliest opportunity. If you decide you would not be willing to take part, I would be very grateful if you could complete the reply slip accordingly and return it, so that I know that this invitation reached you.

Thank you for your time.
Yours sincerely

Hayley Pringle
Trainee Clinical Psychologist
University of Surrey.
Interview Schedule

The questions and prompts contained within the interview schedule (and the order in which they are presented) are tentative, since the interview schedule is not meant to be prescriptive, nor is it meant to act merely as a vehicle to enable the investigator to check her own preconceived notions (see Osborn & Smith, 1998). Rather, the idea is for the participant to give their own view, and if they should highlight issues that the investigator did not anticipate (see Sequeira & Halstead, 2001), there should be enough flexibility to enable these to be explored.

Suggested Research Questions: What are professional carers' explanations of the causes of real life instances of challenging behaviour that they have witnessed? What did they feel and how did they respond? How are their explanations, emotions and responses related in their eyes? Was gender an issue for them and if so how? Did their own gender or that of the client impact on their attributions, emotions or responses? What are their ideas regarding early intervention? If they didn't intervene in the recommended way (i.e. according to behavioural principles) what factors hindered them?

Protocol:

Preamble:

"Thank you for agreeing to take part in my research. As you know I am interested in finding out more about your views regarding the challenging behaviours of service users with whom you work. Before we start, I'll just explain a bit more about the roles that I've had. My training involves several six-month placements in different areas within Clinical Psychology. For example, for one placement I spent six months working as a member of the Hastings and Rother Community Learning Disabilities Team. As part of my role within the team, I visited several service users and their carers in community homes such as this, to try to help resolve difficulties that they had been experiencing, sometimes involving challenging behaviours displayed by the service user.

As you know from the Information Sheet, I am conducting a research project exploring professional carer's views about the challenging behaviour of service users with whom they work, as part of my training. For example I am interested in what behaviours you regard as challenging. I am also interested in your accounts of recent instances of challenging behaviour to which you have been exposed, for example your thoughts about why the service user behaved as they did, what you felt about it, and what you did. I anticipate the interview to last 1 hour."

Then say "Before we begin I'd like you to sign this consent form to show you have agreed to take part"
(Give them the consent form to sign)

Then say “Before we start the interview, I'd just like you to complete this sheet to get some background details”

(Give them demographics sheet to note their age, length of time working in the organisation, length of time working with people with learning disabilities, and whether they have been involved in the past, or are currently involved in any other research studies).

**Areas to cover in interview:**

1) **Explore their understanding of/perceptions about challenging behaviour (to establish a common understanding of what sort of behaviours would be regarded as challenging).**

Could include prompts such as:

“What sort of things do the service users here do that you regard as ‘challenging’?
If the participant talks about a specific incident at this point, say

2) **Encourage interviewee to think of an incident of challenging behaviour to which they were exposed.**

“You've told me about...I was going to ask you about an example of challenging behaviour that you were exposed to. Is it okay to stick with that example or would you like to talk about another?”

Could include prompts such as:

“Can you tell me about an example of challenging behaviour that you witnessed/were exposed to in the course of your work here?”

Whilst listening to their accounts, practice reflective listening skills and note details of
*Type of challenging behaviour
*When it occurred
*Context in which it occurred (e.g. at mealtime, quiet time in afternoon, etc)
3) **Explore their thoughts regarding the cause of the challenging behaviour and the feelings that they experienced.**

As regards their thoughts regarding the cause of the challenging behaviour, possible prompts might be:

"Going back to the example you gave just now about .........., what do you think was the reason for their challenging behaviour?"

"Why do you think they behaved in that way?"

"Why do you think that they ..........?"

As regards their feelings a possible prompt might be:

"Thinking back to the incident that you described that took place on ...... in the ......, when you first noticed ...........how did you feel about it?"

4) **Find out about any action they took and what their motivation was for doing what they did. Find out about whether they believed this to be the best course of action in the circumstances. Also find out what the origin of their understanding was. Be alert for ideas regarding early intervention.**

Could include prompts such as:

"When you first noticed ........what was the first thing that you did?.......And then? ......Why do you think you responded in that way? What did you hope to achieve?"

"I can see that that must have been a difficult situation. Upon reflection, would you have done the same thing again or would you have done something different?"

"What could you have done that would have been less helpful in that situation?"

Then ask:
"You've told me a bit about why you................when.................started to .............., and why you feel this was the best thing to have done in the situation. Could you tell me anything about where you first learned this/gained this knowledge?"

5) **Find out about the interviewee's ideas regarding factors that may have prevented them from responding in the way that they should have responded according to best practice/recommended intervention for that client.**
A possible prompt might be:

"You've explained how when............started to....................you...............and you've also said that actually the best thing to have done would have been to............What sort of things do you think might have prevented you from doing.....?"

6) Find out about whether gender influenced the interviewee's attributions, emotions or response.

Possible prompts might include:

"You've told me about how on..................you saw....................doing....................You've also explained why you thought he/she did...................., what you felt about it and why you.............Some people think that whether someone is male or female can affect how they behave, whereas others think it has nothing to do with whether a person is male or female. Do you think....................'s gender had an influence on how he behaved? If ....................was female/male do you think you would have understood his/her behaviour differently/felt different about it/responded differently?"

Then ask:

"Some people think that the carer's gender can affect how they understand a person's challenging behaviour or respond to it, whereas others think the carer's gender doesn't have any impact on things. Do you think your gender influenced how you understood 's.............challenging behaviour/what you felt about it/how you responded?"

or "Do you think there are differences between male and female carers in the way they understand/feel about/respond to challenging behaviour"

After the above areas have been covered the researcher will ask the interviewee if they have anything they would like to add. The interviewee will then be informed that the interview has ended and they will be thanked for their participation.
Appendix 9
Consent Form
“CARERS OF PEOPLE WITH LD AND CHALLENGING BEHAVIOURS: A STUDY EXPLORING THEIR IDEAS REGARDING THE REASONS FOR THE BEHAVIOURS, HOW THEY FEEL ABOUT THEM AND HOW THEY RESPOND”

Consent Form for Participants

• I confirm that I have read and understand the information sheet.

• I confirm that I have had an opportunity to ask questions and that I have received satisfactory answers.

• I understand that by agreeing to take part in the study I am consenting to take part in an informal interview (and that the interview will be audiotaped for the purpose of analysis).

• I understand that if during the interview I disclose information about abusive practices (such as those that carry high risk of physical or psychological harm to the service user), the interviewer will be duty bound to report this information in line with published guidelines regarding Protection Procedures for Vulnerable Adults.

• I understand that my participation in this study is entirely voluntary and I am free to withdraw at any time.

• I agree to take part in the above study.

............................................................................(Participant’s signature).........................(Date)

............................................................................(Participant’s name)

............................................................................ (Researcher’s signature).............. (Date)
Appendix 10
Demographic information sheet
BACKGROUND INFORMATION

You are being asked to provide answers to the following questions so that those who read the research report can know a little more about the people who have agreed to take part. However, this information will in no way be used to identify you – your identity will remain anonymous.

1. Age

2. Gender

3. Ethnicity

Please choose one of the sections below and tick the box corresponding to your cultural background.

White

- British
- Irish
- Other White background (please give details below)

Mixed

- White and Black Caribbean
- White and Black African
- White and Asian
- Any other mixed background (please give details below)

Asian or Asian British

- Indian
- Pakistani
- Bangladeshi
- Any other Asian background (please give details below)
Black or Black British

Caribbean □
African □
Any other Black background (please give details below)

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

Chinese or Other ethnic group

Chinese □
Any other (please give details below)

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

4. Education

Please indicate your level of education:

Pre GCSE/O Level □
GCSE/O Level □
A Level or other post-GCSE/O Level qualification (e.g. NVQ) □
HND □
Degree □
Post Graduate Qualification □

5. What is your current position at Housing?

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

6. How long have you been working for Housing? ..................

7. How long have you been working in your current position? ..................

8. How long have you been working with people with Learning Disabilities?

--------------------------------------------------------------------------------------------------
9. **Current or prior involvement in Research**
Are you currently involved, or have you ever been involved, in any research related to your current position?

If yes, please give details

.................................................................
....
.................................................................
....
.................................................................
....
Appendix 11
Sample Interview Transcript
Interview with Participant 2

R = Researcher
P = Participant

The following interview was carried out with a 34 year-old White British female who worked as Manager of a three-bed home in a residential area of Hastings, housing three males with learning disabilities and challenging behaviour. This lady had worked with people with learning disabilities for six years. She was educated to NVQ level. She had no current or prior involvement in research related to her position.

R: First of all I wondered what sort of things the service users here do that you regard as challenging?

P: Right er....this is obviously a challenging behaviour house so we have a variety of challenging behaviours from like, everything from, um becoming upset and distressed over incidents, that other people would find quite rational to deal with, they find very difficult...aah...which can be shouting, right the way through to physical violence, throwing things, slamming doors, hitting other people, a wide range of (?)

R: Right....just out of interest how many people have you got...

P: We've just got the three

R: Three okay....right so you've told me generally about the sorts of challenging behaviours that you come across here, and um, I was going to ask you now about a specific example of challenging behaviour that you've witnessed or been exposed to or been involved with whilst in your work here?

P: What type would you like me to describe? A particular incident?

R: A particular incident that's sort of...aah...I guess...something...

P: Do you want that and the history on why it happened or just the...

R: Well I'm going to sort of move...move on to that...

P: Okay um...so...I don’t know how...where you want me to start 'cause you can’t just start with a ‘oh well it started out with him shouting’ ‘cause you need some sort of background don’t you?

R: Um...well I guess you could, you could talk about the most recent incident of um challenging behaviour that’s occurred here or....

P: Okay, well we'll start with Oh...(sighs)...most recent.....obviously most recent obviously is Todd (pseudonym) trying to R...House this morning, he does attend day care on a Wednesday, which is today, so its actually trying to get him out of bed,
have his medication, washed, dressed, packed lunch, ready to go 8 O'Clock in the morning.
Obviously Todd finds this very difficult, because it means getting up when maybe he
doesn’t want to or he wants to stay in bed ‘cause he’s tired...um, and motivation...and
Todd’s response to this is usually to shout, scream....bang himself, hurt himself, um, or
bang furniture, depending on....how he feels, it could be in varying degrees from a
small shout and then okay, through to screaming the place down and....having an
impact on others as well, because, because he’s shouting, the other guys don’t like
him to shout, so they get upset and distressed. So I suppose that’s the most recent one.

R: So, it sounds as if describing Todd he um...a.....displays quite a a range of
um...behaviours like self injury and um...hitting furniture.....?

P: Yes banging furniture

R: Okay when he, um, injures himself does that involve thumping himself?

P: He bangs his legs, he pulls his hair out, he pulls his head, his hair yeh

R: Okay and you were saying about, that happened most recently this morning...

P: That happens most days

R: Okay, so does it happen at, can it happen any time of day or does it tend to...

P: Tends to be when he feels pressured or rushed to doing things when he hasn’t got
enough time, obviously we understand that and we have procedures in place to
actually counteract that, ways to talk to him, excetera excetera which do help.
Obviously he’s just finished the medication reduction, so that doesn’t, that’s not
helping him at all at the moment. Although his medication is now lowered his
behaviours are more....acute, shall we say, intense, but obviously we working towards
that to actually work on that side of his personality now, to.....

R: I see....

P: But we’ll get there in the end

R: So um, this morning, um, did Todd display, did he show all those types of
challenging behaviour that you’ve mentioned or....

P: He didn’t go as far as self-harming I don’t think, but there definitely was a lot of
shouting

R: Okay so a lot of shouting this morning...

P: A lot of shouting and screaming. So again its almost like a routine that he has to
go through to achieve it. He doesn’t actually become distressed by it its almost like a
routine...to get him started sort of thing
R: I see...

P: I mean obviously we tell him, hey we were, dis, I mean he's been distracted sometimes, obviously, he will exhibit challenging behaviour, but that particular incident was almost like a routine, gets it out of his system, and then he's right, once its happened he's like 'Woo yes I'm happy now, the start of the day' sort of thing. He's ready to go, and he's quite happy now, at a party, having a wonderful time (laughs) I haven't heard anything to the contrary so (laughs) he's having a good time!

R: (laughs) so this morning he was shouting and screaming but at other times he might actually start to um hit his legs or hit furniture or....

P: Um, he can do, I mean (sighs) depends how he's feeling, what's upsetting him, what he's got on his mind if he really don't wanna do it and then, obviously you say well fair enough. Again its knowing him, its experience of working with him, its, you know how far you can take it....

R: Ummm

P: Knowing if he's just going through the motions or if he really really is upset. Again that's to do with staffing levels, its to do with who's on shift, obviously if he's got a favourite, if I go up there and say 'Oh would you come and go down to the car' he'd probably be quite happy 'cause he responds well to authority figures so his key worker, Team Leader, Manager are very important to him, whereas anybody that's not either a Team Leader, a keyworker, if they're on shift then its harder for them, because he doesn't see them in that sort of light

R: Mmm, right, I see, so it sounds like. So it sounds like Todd, um, well its times when he feels, as you say when he feels pressured that he starts to show these sorts of things

P: Yeh can be that...

R: When he screams and shouts like he did this morning, what sorts of things, does he actually say words, or, what sorts of things does he say?

P: He usually just says the sort of thing 'No I don't want to do it, no, you lot only work here you can't tell me....you know, that sort of thing...'No No I'm going to wait 'till tomorrow, no I don't wanna do it, leave me alone'

R: I see

P: A lot of it he blames on Fifi Watts who's his um, imaginary friend. Again she's he's conscience and is an excuse as well, depending on how its viewed.

R: So she doesn't actually exist?

P: She did exist many years ago, but she doesn't exist anymore – well she's not in his life anymore shall we say
P: Oh no, she is his conscience, she is his friend. She is his continuity as well. You know with clients with learning disabilities, their routines are their only...their only consistency. Staff are changing all the time, houses, they may move house. There’s lots of changes in their...you know not as much disabilities but anybody that’s in a nursing situation aren’t they? There’s a lot of changes you know if you went to any hospital, people are coming in, coming out, staffs are changing, you’ve got new doctors, new...new friends coming, going so the only consistency they have is their own routines and their own way....their own things

R: Yeh...yeh, yeh. So um, that example that you gave me this morning, that was um, er a good example and a recent example of the challenging behaviour that you’ve been exposed to, um does Todd do anything outside the home or is... are his behaviours normally limited to the home?

P: Mostly in the house but he can become excitable when he’s outside. Again, there’s triggers, and again you know that if he does become excitable you say come on Todd lets go and get a cup of cola, chewing gum, he’s quite happy with that, ‘cause you won’t you know, um, obviously you don’t take him anywhere near football grounds ‘cause he just gets really excitable so, you have to steer away from that unless he’s really prepared (laughs) to go, but no, I mean he’s probably quite good in the community

R: Okay, so, perhaps going backwards from most recent time that you saw Todd exhibiting challenging behaviour. I was wondering if you could tell me about the last time that he, actually, self-harmed or, or um started, damaging furniture or attacking furniture?

P: Ahh...oh gawd! (laughs).....er, probably last week some time. Can’t give you specifics but probably last week some time. Probably um....I know he had a very bad episode over the weekend with his bowels, because he doesn’t like using the toilet he’s got a psychological aversion to using the toilet. So obviously it got so bad that he had to go, and then he made a bit of a mess, so he got really stressed ‘cause his clothes were dirty and then etc etc so that caused him to self harm ‘cause he was so upset with himself, but obviously upset with what he’d done and....which he shouldn’t be but he is....that’s the way he sees it.

R: And were you actually there at the time?

P: No...I’ve been there many times before. This is quite a common occurrence every sort of four or five days that this happens so....

R: When was the last time that it happened that you were actually there?

P: About a week and a half ago

R: Could you tell me more about that?
P: Again Todd has a psychological aversion to using the toilet. So he holds it...holds it in. He won’t use, have his bowels open for days on end, and then suddenly he’ll have to go, which means, which means that when he does go he tries to clean himself and be hygienic but he fails totally. He’s been through all the local...he’s been through the programmes of the self-help skills, and we’ve got a pictures on the toilet saying ‘this is your toilet you can use it’ and Mark and Kim the bosses have got pictures on saying ‘you can use this toilet, your allowed, this is your toilet. We’ve got all those reinforcement things in, to make him feel better about going, but again, he goes to the toilet then he, doesn’t clean himself properly so he gets it on his trousers and he hates having anything spilt over his trousers or his clothes because he’s quite proud of his appearance, so as soon as he gets any dirt on his trousers, or faeces in his trousers, then obviously he gets really panicky ‘cause we want to wash them and then he doesn’t like staff washing them ‘cause he thinks that then they will tell him off, so he still gets...then he starts talking, and then exhibiting (demonstrates slap to the head) then he starts getting agitated, which starts him shouting and then you start saying come on Todd, come and talk to me, calm down, ‘I don’t wanna talk to you’ you know, and then he becomes more and more agitated and then he’ll go up to his room and slam the door and start banging on furniture you know ‘leave me alone, you can’t wash my clothes’. We’ve put you know nice little buckets in his room so he can put his clothes in and be discreet and he’s got bags and stuff. We’ve been through that but that still doesn’t make him feel any better. It lessens it, but he’s not more.....and then of course he sits up there and he (demonstrates slapping head onto legs) on his legs and he goes ‘look at my hair, look at my hair’ and its all bleeding ‘cause of the scabs all over his head so...

R: Right so was that typically what...what happened the other day when.....

P: Yes! That’s typical...typical Todd...sounds rather blasé, I don’t mean to be blasé (laughs) but its typical....but I mean that’s a lot less than...used to...actually trash his room with the furniture and...you know banging the doors in the wardrobes, and the panels in the doors...if you actually look at the door frames, that’s why they’ve all cracked...

R: Oh right, yeh....

P: You see...um, but he doesn’t do that any more, we’ve sort of like managed to get it down to a lot less than what it used to be a few years ago...we’ve achieved quite a lot with him.

R: Brilliant...so that incident where you described he messed himself and he ended up going upstairs and banging the furniture, you were actually around at that time?

P: Yes, yes

R: Okay....I was wondering if we could perhaps focus on that incident rather than the incident this morning....

P: Okay
R: .....or maybe we could talk about them both (laughs) if we’ve got time!

P: What do you need to know? (laughs) that would be telling (laughs) Me going round the bush, you know (laughs) What do you need to know? (quieter voice)

R: I was wondering what your thoughts were about the reasons for the challenging behaviour first of all if we could talk about the incident a few days ago when he a...

P: ... had the accident, yeh. The reasons? Ooooh! Again I think its just he has — well it’s a know fact that he has a psychological aversion to using the toilet. He thinks this is not his house...he thinks that...this doesn’t belong to him...he thinks that he can’t use the toilet. Everything else is fine he doesn’t mind using the tele or the chairs or anything but the toilet, but he’s al...he was like that when he came into the company, so that hasn’t changed

R: Right...so he feels uncomfortable about using...or you think he feels...

P: We know that he feels uncomfortable about using the toilet. He thinks it’s a dirty thing to do, he thinks that its not right, it’s a dirty thing to do....and also, that is reinforced ‘cause when he does go, he has....he doesn’t...he has accidents, which makes him feel even worse! It’s a....it’s a never ending cycle.

R: Yeh I see...so just to check that I’ve understood this right, he feels uncomfortable about using the toilet...

P: Yes he doesn’t feel it belongs to him and it’s a dirty thing to do

R: It’s a dirty thing to do which means he doesn’t actually go when he needs to go...

P: No he just holds it and holds it and holds it ‘till he can’t hold it any more

R: Right and then he has the accidents...

P: And then he...well he goes to toilet, but of course he goes so much and it comes out in such a....a lot, shall we say, that a....well he holds it and then you get a lot of overflow, and then you...you like, your faeces you know...

R: Yeh when you get sort of the softer...

P: Yeh and you get overflow coming down the sides so...

R: Right, yeh...so this um....I’m quite interested in this feeling he has that um, it doesn’t belong to him and you were saying that he feels that about the house...

P: No just the toilet

R: Just the toilet
P: The toilet...well, he said its Mark and Kim’s house, but the actual things in it he considers his...

R: Okay, so the things in the house are his...

P: Yeh are his but the toilet is not

R: Do you have any understanding about where that’s come from...that idea of his?

P: Well...again I think its a lot to do with learning disabilities, being moved around a lot....having different services, I know Todd’s only been with us for.....five years and he’s...what, fifty now so.....that’s a lot of time, I mean a lot of learning disabilities are the same, they only spend maybe two, three, five years in a company, in a service before they’ve had enough and they move on to somewhere else. You don’t really get a lot of long term....for various reasons, sometimes it might be that they just do very....a lot of ours is that they’ve done so well that they go on to independent living...not saying its always like that some of them do go downhill and we can’t care for them anymore because of their problems but....it might be I mean I’ve had one who wants to be near his sister so he’s moved on, but he was with the company ten-twelve years, so....but there’s always that different staff, different....different house yeh

R: Okay, so, I was wondering, thinking back to that last incident where he um, had the accident, was, that...that was about last week did you say?

P: Happens about every five days

R: Happens about every five days...but the last time it happened when you were around was...?

P: It was about a week and a half ago

R: So thinking back to that time when you were around and that happened, how did you actually feel about it?

P: I think I’ve worked in learning disabilities for such a long time that it doesn’t really affect me too much at all. Its just part of their care, and part of the support that I give to them. It doesn’t upset me, it doesn’t make me feel...it just makes me feel quite sad, that you want to do more to help, and that is what my job is is actually to help to put in stools programmes, and get him seen by the doctor to give him some tablets maybe and help him out....

R: I see so there’s an element of sadness about what’s happening and...

P: Yeh, and there’s pressure from the other staff ‘cause they expect me to....find the problem ‘cause obviously there’s Todd shouting and they don’t like it and they don’t like clearing up after him even though he has got stools programmes to do with him cleaning up after himself anyway....tried that already! (laughs)...you know they
expect me to find a solution...which there isn’t one. All we can do is lessen it as much as possible, and we have done that...but...so I suppose there’s all that pressure.

R: Right so there’s pressure from them to actually....

P: Solve the problem! (laughs)

R: Solve the problem (laughs)

P: When there out scrubbing the carpets...because he’s had an accident he’s walked it all through the house sort of thing...

R: Do you feel that how you feel about it has changed ‘cause I know you said that you worked with people with learning disabilities for a long time...I just wondered if you could remember a time when your feelings were different...?

P: Not really...not really ‘cause I’ve always ‘cause I’ve always done nursing at some point, of some description (laughs) be it at Day Centres or elderly or Alzheimer’s or mental health or nursing homes...its always been....I’ve always felt that way

R: So that experience that you’ve had for a long time....

P: Yeh I’ve always felt like clients should be able to be...I’m there to support....I’ve always had the feeling I am here to support you in your life, and that’s what I’m here to do, and to make your life as nice as possible

R: So that the sort of feeling I guess that...I don’t want to put words in your mouth but...I guess what you’ve already said that you felt a bit sad about it but also that you wanted to help...

P: Yeh

R: Okay. Still sticking to this incident where Todd had the accident, what was the first thing if anything that you did at that time?

P: How do you mean? What do you mean calming Todd down...or do you mean...?

R: I guess um, I’m....

P: When it first happened?

R: Yeh, like the last time that happened and you were around...

P: Right well the first thing you’d hear would...actually the first....you wouldn’t hear anything, but the first thing you’d notice would be the smell coming out of Todd’s room, or his clothes being stained, or Todd had changed his clothes, and then you’d go up and say “Hi Todd, are you alright?” and he’d go “yes, yes, yes, yes, yes” and I’ll say something like “How ya doing?” And then um, if he didn’t mention it himself
you’d probably say something like “Well I think you really need to change your clothes” sort of thing...

R: Okay, so....

P: You know, you really need to change your clothes, and that’s when it all sort of starts “I’m not changing my clothes” and (sighs) that sort of thing. Or if you’ve actually caught him walking, call him, dirty, after he’s done it, walking through the house, and you say “Aoh Todd, I don’t think you should be walking there, I think you’d better go into your room because you’ll make, sort of thing...and then he’ll like he’s been caught, “Aw do you need a hand there Todd I’ll go and get...” you know “Do you want me to help you out I’ll go and get a clean cloth or something and I’ll go and get it for you” And he’d say “Yeh Yeh Yeh” and then you’d go and get it and then he’d go “No No No No No I’m not doing it!!!! (laughs)

R: I see...

P: It depends. It really depends on his mood...you.....and again it depends whose on, ‘cause Mark (another carer) will go “Aww Todd you know, come on then lets go and sought you out mate” and he’ll go “ok alright then” (laughs), and he’s fine, and then another day he might go “No, I don’t want you, don’t want you, go away, leave me alone” you know...it depends

R: So not always the same with particular carers....

P: Its different...different moods

R: Yeh, okay. So the first thing that you would usually do would be...

P: Well something like “Todd, do you want a hand, do you need some help there?” you know, that sort of thing.....or it might be “Aw Todd lets get this sorted out and then we’ll go out for lunch” or “Aw yeh sort you out, Aw you change those and then we’ll go out in the car” sort of thing or....so there’s usually something fun at the end of it, something positive or, yes we’ll sort you out or just do this and then how about we’ll go down town and get you a nice bit of chocolate, you know, so there’s always something positive at the end of it....reward...to lessen...usually something about coca cola and chewing gum! (laughs)

R: (laughs) so they’re his....

P: Yeh his reinforcements (laughs)...coca cola and chewing gum....everybody’s got their own....chocolate...

R: Yeh everybody’s got their...chocolate I can certainly sympathise with that (laughs)
My next question probably sounds a bit redundant now but I was going to say why do you think that you responded in that way but um....
P: Well I think....I think everybody's an individual, and I think everybody responds in their different ways to different situations, and again its how you feel as well, 'cause one day I might be feeling really patient, and another day you might feel.. be feeling a bit stressed, might' en you, so...you might not be as patient as you might be most days, shall we say, so everybody has their different moods, but in general, I must say...that... through experience we have written guidelines and procedures so everything that Todd does is recorded, is written down and everything that staff should say in response, to get him motivated to achieve the goal, to whatever, is written down, and staff read these guidelines and we're always reviewing and adding to these so people are always putting their experiences in and staff it doesn't matter about their personal preferences. In the end these are the guidelines that nine times out of ten work, and these are what people...this is what we follow. And it doesn't matter if what your personal opinion is....'cause we're not here for personal opinion, we are here because this is what works for Todd, this is the way to get him motivated, this is the experience of not just the staff that are here at the moment but the staff that have worked here in for six years...that have gone, moved on years ago, but when they worked with him they knew that this worked, that one of the ways to get him motivated to go to .....House in the morning without any shouting was to say “Come on Todd lets go up the garage and get a can of coke before we go and you can take it in your packed lunch” Cuts out all the shouting! (laughs) It works. Doesn't work all the time, but if it works half the time its got to be worth something hasn't it?

R: Yeh, yeh definitely....so making use of the experience of staff who have known Todd who have worked here for quite a long time before...yeh, and you say that the written guidelines that are there and that are perhaps based on what the staff have done...

P: Yeh and they're always added to and reviewed so....

R: Yeh, yeh I see...it sounds like when for example with the incident where he had an accident, when you say to him something like oh come on shall I help you with or shall we get changed or whatever sounds like as you say there's a reward most of the time at the end of it...

P: Yeh, we try to have a...ah usually well, everything we do with changing behaviour usually has some sort of positive.....I think you have to...doesn't matter what it is, you have to have a positive something at the end of it. Its like when you have your reviews don't you, you have the good, the negative, but you always end on a positive don't you...it just makes the person feel better at the end of it...you've got your point across, but you've ended up in a happy....'cause for our clients, to end up with a....to end....to finish on a bad note is just for them to brood on it and end up with more challenging behaviour throughout the day....you have to sort things out pretty quick. The worst thing you can do with challenging behaviour is just let them think on it and brood over it and to let it mull over in their minds because it just adds to more problems. You need to get it sorted.

R: Right, yeh, so there's an element of needing to um prevent them from escalating...

P: Yes, yeh
R: Okay, upon reflection, would you have done the same thing again, you know, if it happens again with Todd and he has an accident?

P: I would do the same sort of thing. We’re always looking...I dunno we’re always looking for new ways to review and to try new things....would I do the same again...basically yeh

R: Okay

P: Because we know that that’s what works, but we’re always looking for new things. I think if you say no, then you’re not looking to progress are you? Because I think you can always can find new ways...new ways to motivate..

R: Yeh, so always open to new things but essentially...

P: Yeh it’s the only way that really works for Todd, there’s no point in trying yeh we looked at other ways but they don’t work.

R: Right, okay, what could you have done that would have been perhaps a bit less helpful in that situation do you think?

P: Less helpful?

R: Yeh

P: Oh that’s easy I could have gone in there like a bull in a china shop and said you’re a dirty old man and you can....or any of that approach Todd what have you done? Todd oh you know oh my God you know this smells. Anything...anything negative would just not have helped him. Some people respond well to that approach but not Todd. That very positive...that sort of like matter-of-fact approach oh dear here we go again! sort of thing, you know...aw that that no just doesn’t work well with Todd...can I rewind that bit ‘cause that didn’t come out quite right at all! (laughs)

R: It sounds like what your saying is that the matter of fact approach works...

P: Doesn’t work very well with him

R: Doesn’t work....ahh...I guess it um...

P: With Todd its more, he likes a jollier person “How ya doin matey?” He likes to be one of the lads. That matter-of-fact just doesn’t work with Todd you need to be happy and...

R: Right, so by matter-of-fact, you mean sort of quite negative...quite...

P: Not negative, but just sort of like “Aw Todd yeh right we need to change your trousers, come on then lets go and do it” Is not going to work half as well as “Come on then matey lets get upstairs...um...ooh that’s a nice thing on your wall...come on
lets get this done and then we’ll go out” He prefers that sort of side of things, rather than the “come on then Todd you’ve got to go and do this”.

R: Ahh I see, yeh

P: That more professional...he doesn’t do well with the professional approach, the more reserved professional approach doesn’t do well, he likes the matey, the jokey that gets him further...well you’ll get further with that approach with him, in everything that he does....he wants to be one of the lads.

R: Okay so that’s the sort of approach..that’s um...I really am pleased that you highlighted that

P: The other gentlemen are different, totally, they don’t like that approach at all, but um...

R: Right, so he likes that sort of quite jokey, jovial sort of upbeat approach

P: Yep, yep, oh yeh, he likes to be one of the lads

R: Okay, right could you tell me anything about where you first gained the knowledge that you’ve got about how to deal with the situation when he has an accident?

P: Where I gained the knowledge?

R: Yeh

P: Well I suppose working, coming to work in the house from other people that were here, I suppose...and reading through the procedures and the behaviours, and now writing (laughs) and making sure that the staff, other staff are reading the behaviours and having to write them myself (laughs) and amend them with the keyworkers and stuff so...yeh

R: Okay, so staff that were already here when you joined the team were quite helpful and the written procedures. Just out of interest have you attended training courses like SCIP or anything?

P: We’ve done...yeh in this particular house we have to do more training than the other houses that does include SCIP we have been up to ..........House (CLDT base) and worked very closely with the mental health team up there so we do go on training courses specifically for mental health, challenging behaviour, and also they run courses on because the clients under them are very close they actually run courses on those particular clients...understanding clients

R: I see, um course on those....

P: Just particular...not courses but we just go up and discuss, we have like open sessions on...
R: Ahh is that .............. (organisation that participant works for) that actually holds these courses?

P: They do, some of them do, and the keyworkers and stuff, they run their own courses on understanding particular aspects of the client, but again the house also do a lot with other clients, you know understanding their behaviours, so the staff you know we had one recently where all the staff went up, just to talk with the team up there about a particular client

R: Ahh right, and are those things helpful as well or is it more...

P: I think there helpful to the newer members of staff I think its sort of like they understand where the behaviours are coming from, why they think like they think or why you get that reaction to a certain situation, where the roots are coming from shall we say...

R: Right so newer members of staff perhaps benefit quite a lot from that

P: I think all staff but especially newer ones, yeh.....if they haven’t done this work before yeh

R: Yeh...okay...so you’ve explained about when Todd had the accident the other day and what you usually do and why you do that. Are there any barriers to best practice or factors that would hinder implementing the intervention that you do implement?

P: For that particular situation?

R: Yeh

P: Barriers....ummm....no I don’t think so. I’m trying to think of anything that we could have done that we haven’t already tried....the on....I suppose....are you talking about in an ideal world?

R: Yes, I guess....

P: Right in an ideal world, obviously Mark and Kim the big bosses coming down everyday, and showing him the toilet (laughs). If you’re talking about an ideal world, that would be...that would be really nice, umm....

R: Right how come....what would be the motivation behind that?

P: To make him go...he would use the toilet for them because he....I mean we have a bowel chart in there and he has his particular phrase for using the toilet – he calls it...squeeze. So every day we ask him have you had a squeeze or go and have a squeeze ‘cause its his reference to use the toilet but if Mark and Kim came down and said have you had a squeeze he’d be up there like a shot! (laughs) ‘cause as long as they’ve given him permission, ‘cause he sees them as the ultimate authority so he’s...cause he loves people in authority as I’ve said to you before about keyworkers
and stuff he listens to them, managers keyworkers and the senior management team of

Housing and Mark and Kim are obviously the proprietors so in an ideal world if Mark and Kim came down every day and said Todd can you go and use the toilet (laughs) that would be wonderful. Umm...but anything else...no I guess he’s had skills programmes...

R: I was just wondering how about more generally with him and perhaps with other clients as well...some barriers to implementing interventions....things that might hinder...

P: No...no...’cause he’s got the staffing and they make the effort and he’s got the good keyworker whose been with him for years so...he really abdicates (?) well, so it’s not as if he hasn’t got that support there.

R: Okay, so good staffing, and a good keyworker as well

P: Yeh, you can’t help it ‘cause he is just so loveable. He is just a lovely client as well. I know you shouldn’t say that but some clients you have a rapport, are more close to, are more special ooh no that doesn’t sound too good! (laughs) Cut that out! (laughs)

R: No I mean its important to think of the variables that affect...

P: Yeh...they’re more...not that you don’t want to do more for them but just...there’s something about them that just makes you laugh a little bit more or just endears you to them a little bit more...and he’s one of them (laughs) he’s just lovely you can’t help just love ‘im to bits

R: (laughs) So that sort of something about them that endears you to them more...

P: Yeh he’s a sweetheart Todd, he’s so lovely

R: Do you think that affects how you feel about their challenging behaviour at all or how you respond to it?

P: No, no

R: No...?

P: No because I’ve got three clients here with challenging behaviour and I feel exactly the same way I know the other staff don’t, but I’ve been here long enough, and know them well enough, that it doesn’t bother me....and I understand how to handle them. I think newer staff find it more difficult obviously, but then again I’m here to facilitate their training and understanding, so...which is what we try to do

R: Yeh, yeh...okay. I’m going on to the last couple of questions now. So you’ve told me about Todd having his accident and you’ve explained why this might happen and what you do about it. Do you think Todd’s gender has an influence at all on his challenging behaviour?
P: It doesn’t have an influence on his challenging behaviour but he is a man’s man. He sees men as superior to women...so a man...a woman in authority is okay its acceptable ‘cause I’m in authority, I’m the manager, he’s my deputy and he comes and helps me in the office so I’m okay, but in general he sees women as inferior so a man would have more ability to motivate him or he would listen to a man more than he would a female member of staff

R: So perhaps if a man were to intervene rather than a woman if it wasn’t you then...

P: Yeh, yeh...and most...I mean I’m saying as a manager he doesn’t listen to me some of the time ‘cause I’m a woman. He goes No, no you’re a lady, you don’t know anything about this...especially when its things like he’s talking about football, trains, I’m a lady, I know nothing about football, and I’m ignorant (laughs) and that’s fine, he doesn’t want me...you just have to understand that that is Todd..... and he’s a man’s man ‘no you know nothing about football!’ (laughs)

R: Yeh...so as you say he’s a man’s man (laughs)

P: Yeh, so I suppose that’s the only thing I would say

R: Okay, so if he were a female do you think you would have understood his behaviour differently or thought about it differently at all?

P: No, no ‘cause I’ve worked with all different clients....that’s it

R: Okay, so that wouldn’t really make any difference?

P: No...are the only difference it would make is actually in the interventions, because a lot of them being females have got longer nails so when they scratch you you have to be a bit more careful, that sort of thing, and men tend to punch where women will tend to go for your jewellery. So that would be the only difference in behaviours. Men tend to...I find the behaviours that men tend to sort of like punch and hit, where women tend to grab...they tend to be more grabby, mainly....but that’s just my opinion

R: So there’s a difference in the aggressive sort of challenging behaviour in the way that the aggression is demonstrated...

P: That’s just my personal...(laughs)

R: But that’s really important because you know you’ve obviously worked with these clients for a long time so...

P: And again, the other way round, is that if you have to use physical restraint of any sort even if its just touch control to get ya ha...their hands out of the way obviously women tend to wear more jewellery and tend to wear loose fitting clothes, so they’re harder, whereas men tend to wear jeans and a T-shirt, which are quite tight fitting, you can get a hold...not saying get a hold...well yeh you can get a hold if your escorting
whatever where females, they tend to wear more looser fitting, and especially in the Summer where they show more skin, its harder, you have to be a bit more careful, especially with jewellery and stuff

R: Yeh, okay...um...some people think that the carer’s gender can affect how they understand a person’s challenging behaviour or how they respond to it, whereas others think the carers gender doesn’t really have any impact on things. Do you think the fact that you’re a female influenced how you or influences how you understand Todd’s challenging behaviour?

P: No, I don’t think it makes any difference. To be perfectly honest, male or female working with females or males, doesn’t make any difference...I’m, I’ve had...I mean this house is all men, male staff. Some of them are good, some of them are sensitive, some of them aren’t, some of them are creative, some of them aren’t. I don’t think it makes any difference....um but no I don’t think, I honestly don’t think it makes any more more caring or sensitive ‘cause I think if a male comes into this environment he’s got to be fairly caring and a sensitive person to want to do this job, so you’ve already crossed that boundary where your not taking....and I think it’s the same for women as well, that you wouldn’t come into this job unless you had some sort of .....willingness to do the job...um...but especially from the male point of view, knowing that your going to have to do a bit more personal care and it is more....feminine side of one’s character shall we say....but no, I don’t think it makes much difference.

R: Okay so it sounds like you don’t feel that it makes a difference to you in terms of how you as a woman feel about it or respond to it. I was quite interested in when you just said that this is an all...

P: Male house yeh

R: All male house and that they’re all...

P: All the clients are male

R: All the clients are male

P: I’m the only female here (laughs)

R: So all the staff as well

P: Yep they’re all male

R: All male, so is there any particular reason for that, you know, male female...

P: Ahh, mainly ‘cause of the physical restraint that can or needs to be required....umm...but also because one particular client can become very emotionally attached to females, which leads to terrible problems with jealousy...and um...with um...when that....when they do, have become attached, we’ve had this before, with two previous females, and um, when that females’ been with one of the other clients
he's become extremely jealous, resentful that they're spending time... not with them, shall we say, which leads to terrible challenging behaviour (laughs) and that leads to real problems all round

R: Right, so experience has shown you that with this particular client, females...

P: Its not a good idea

R: He tends to set up some sort of relationship that, well he...

P: Perceived...

R: Perceived relationship

P: The relationship's in his mind, yes, which is very very difficult, which leads to real terrible challenging behaviours because he gets jealous, which makes him really upset and physically violent, he upsets the other clients because he's shouting at them, who become upset, and then they end up shouting at each other, and then they become physically violent, then the other client hates the shouting, who becomes, then that kicks him off, because he hates the shouting, so he's really upset, and then it ends up that it all calms down, 'cause we calm the situation down, but they won't come out of their rooms to talk to him, and then he... then... he gets upset because nobody else is talking to him (laughs) they won't talk to him, so he becomes upset, because he thinks if he apologises, everything will be alright, but its not. They still hold resentment, but he can't understand that, so they in their rooms ignoring him, he says hello they ignore him, so he gets upset and it all starts all over again! (laughs)... joy joy joy (laughs)

R: (laughs) Ahh oh dear, yes I can see why there are very good justifications for just having male staff, yeh

P: Oh it happens with males as well but not to the same degree, you don't get the same sort of... levels

R: Right okay yeh

P: But then again all staff are aware of that so you have to be careful that you know, he's on with a different person every day, and not too much time on an activity spent with one person, that he doesn't become attached to that one person, relies on that one person all the time so...

R: I see so there's ways of organising things so that...

P: Yeh we try to organise times... and make sure that one person doesn't take him shopping all the time 'cause then it looks like that one person is the nice person 'cause they're always taking him shopping sort of thing... its its all different, different ways, environmental and... you know...

R: Managing situations, yeh... okay, well we've now reached the end of the interview – have you got anything further you'd like to add?
P: No, I don't think so

R: Thank you very much for taking part
Logbook of Research Activity

September 2002 – July 2005
All 3 Years
<table>
<thead>
<tr>
<th>Date</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>02/10/2003</td>
<td>Conducted a comprehensive literature search</td>
</tr>
<tr>
<td>21/10/2003</td>
<td>Conducted a literature search on the topic of &quot;neurocognitive processes&quot;, &quot;symptoms&quot;, &quot;interpretations&quot;, &quot;work with psychiatric/psychological disorders&quot;, and an evaluation of symptoms in anxiety and depression.</td>
</tr>
<tr>
<td>28/09/2003</td>
<td>Conducted a literature search on the topic of &quot;waiting time and attendance at initial appointment&quot;, &quot;waiting time and attendance at initial appointment as part of SRP&quot;, and &quot;visiting time and attendance at initial appointment as part of SRP&quot;.</td>
</tr>
<tr>
<td>April - June 2004</td>
<td>Critically reviewed the literature on &quot;visiting time and attendance at initial appointment as part of SRP&quot;.</td>
</tr>
<tr>
<td>02/10/2002</td>
<td>Formulate a specific research question. Following discussion with research project leader (RPR)</td>
</tr>
<tr>
<td></td>
<td>1. Research Project (RPR) challenging behaviour as part of my research. Behaviour towards people with LD and models exploring to explain care staff's responses.</td>
</tr>
<tr>
<td></td>
<td>2. Critically reviewed the literature on &quot;waiting time and attendance at initial appointment&quot;, &quot;waiting time and attendance at initial appointment as part of SRP&quot;, and &quot;visiting time and attendance at initial appointment as part of SRP&quot;.</td>
</tr>
<tr>
<td></td>
<td>SKILL/EXPERIENCE ACQUIRED</td>
</tr>
<tr>
<td>Month</td>
<td>Event</td>
</tr>
<tr>
<td>-------</td>
<td>----------------------------------------------------------------------</td>
</tr>
<tr>
<td>Sept 2002</td>
<td>1. Proposed a brief research proposal for a Primary Care Service.</td>
</tr>
<tr>
<td></td>
<td>2. Formulated specific aims of my MRP.</td>
</tr>
<tr>
<td></td>
<td>2. Formulated research questions with field and specific aims of my MRP.</td>
</tr>
<tr>
<td>April 2004</td>
<td>1. Obtained approval for research for a clinical governance.</td>
</tr>
<tr>
<td></td>
<td>2. Formulated the project to ensure clarity of the research questions.</td>
</tr>
<tr>
<td>Apr/May 2004</td>
<td>1. Produced a detailed research proposal.</td>
</tr>
<tr>
<td></td>
<td>2. Produced a mini literature review.</td>
</tr>
<tr>
<td>Date</td>
<td>Event</td>
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<tr>
<td>------------</td>
<td>-------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>23/05/2003</td>
<td>1. Having used SPSS to establish if the variables are significant, both categorical and scale variables, the data collected for survey questionnaires are included in the research project. The data file in SPSS is saved.</td>
</tr>
<tr>
<td>06/05/2003</td>
<td>1. Set up a data file in SPSS to analyse</td>
</tr>
<tr>
<td>Dec 2004 to Feb 2005</td>
<td>Collect data from research participants.</td>
</tr>
<tr>
<td>Feb 2004</td>
<td>Ethics Committee</td>
</tr>
<tr>
<td></td>
<td>a) The University of Sydney Research Ethics Committee</td>
</tr>
<tr>
<td></td>
<td>b) The Local Research Ethics Committee</td>
</tr>
<tr>
<td>Oct/Nov 2004</td>
<td>Obtained from two sources: ETH and MRP was approved for the MRP, ethics committee approved from a research ethics committee.</td>
</tr>
<tr>
<td>July 2004</td>
<td>Potential participants about this issue: request to provide more information to ETH's sheet was amended in response to IREC's disapproval dispute procedure. Information sharing action in response to participant's ethical concerns associated with potential ethical concerns associated with</td>
</tr>
<tr>
<td></td>
<td>I. Regarding the MRP, there were no concerns.</td>
</tr>
<tr>
<td>May 2004</td>
<td>NHS's guidelines on ethical practice and consent form for MRP, consultation with</td>
</tr>
<tr>
<td>Date</td>
<td>Event</td>
</tr>
<tr>
<td>------------</td>
<td>-----------------------------------------------------------------------</td>
</tr>
<tr>
<td>20/10/2003</td>
<td>Present research findings/plans in an audience</td>
</tr>
<tr>
<td>May/June 2003</td>
<td>1. Research on children and young people with LD and challenging behavior; interpret in the light of existing models and evidence as a result of the IPA were presented to the audience. 2. With regard to the MRP themes: consecutive lack of statistical power, sample sizes/insufficient statistics, and ongoing interpretation in the light of small project was surmised and results were interpreted results from data analysis.</td>
</tr>
<tr>
<td>June 2005</td>
<td>Summarize results in figures/tables</td>
</tr>
<tr>
<td>April/May 2005</td>
<td>Analyze qualitative data.</td>
</tr>
</tbody>
</table>

Note: MRP = Multi-Regenerative Process; IPA = Interpretative Phenomenological Analysis; LD = Learning Disability.
Specific techniques advocated within them,
either directly through application of
practice at various stages of my training.
These papers have influenced my clinical
psychologist, I 7 - 92.
I. Morgan, A. (2002). Beginning to use a

Apply research findings to clinical practice
during your training which influenced your
(Provide examples of 3 papers published)

<table>
<thead>
<tr>
<th>Proposed for Oct/Nov 2005</th>
<th>Viva Voice arranged for 13/09/05</th>
<th>Defining Research project in detail</th>
</tr>
</thead>
<tbody>
<tr>
<td>I plan to submit the MRP Report for examination in September 2005</td>
<td>V I I I defined MRP as oral examination on</td>
<td>Define research project in detail</td>
</tr>
<tr>
<td>1390 - 11/11/05</td>
<td>13/9/05</td>
<td>11/9/05</td>
</tr>
<tr>
<td>May - July 2005</td>
<td>May 2004</td>
<td>May 2004</td>
</tr>
</tbody>
</table>
| Production of the final report | Several drafts were submitted and | Powerpoint
| This service. | The qualitative research project was | The presentation year group decided
| Presentation supported a formal | Written up as a formal report. Several | to present the MRP as a formal
| formal communication and a flexible approach | drafts were submitted and | report. Several drafts were submitted
| & This necessitated open | submitted and | and a flexible approach.
| discussion within the group with other group | discussion within the group with other group |
| The qualitative research project was | This necessitated open | Discussion in the group with other group
| Several drafts were submitted and | discussion within the group with other group |
| | Discussion in the group with other group |
| May 2003 | May 2004 | May 2004 |
| Powerpoint | The presentation year group decided | Powerpoint
| to present the MRP as a formal | to present the MRP as a formal | |