Being healthy: a qualitative study exploring the understanding and experiences of adults with a learning disability

by

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INTRODUCTION TO THE PORTFOLIO

This Portfolio contains a selection of work completed for the PsychD in Clinical Psychology at the University of Surrey. The Portfolio is organised in two Volumes. Volume I comprises the academic dossier, which contains four essays covering core specialties; the clinical dossier, which contains summaries of all six placements undertaken (four core placements and two specialist placements), and summaries of five clinical case reports; and the research dossier, which contains the service related research project undertaken in year one, the qualitative research project completed in year two, and the major research project completed in year three.

Volume II comprises the clinical dossier of the clinical work completed. This includes five case reports (covering four core and one specialist placement), summaries of all the clinical placements undertaken, and relevant placement documentation including placement contracts, logbooks of clinical experience and placement evaluation forms. Due to the confidential nature of the clinical material within this dossier, Volume II will be held within the Psychology Department of the University of Surrey.

The work presented in the portfolio reflects the range of client groups, presenting problems and psychological approaches experienced during training. The order in which the work was completed is retained in the portfolio, thereby illustrating the development of clinical skills over the course of training.
ACADEMIC DOSSIER

Overview
This section contains four selected essays from the core client groups studied in years one and two of clinical training. These essays critically examine the theory and practice of a range of psychological approaches to various issues experienced across the lifespan.
Compare and contrast the evidence base for two different theoretical models of eating disorders. What implications does this have for the delivery and provision of clinical services for people with eating disorders?

January 2002

Year 1
Compare and contrast the evidence base for two different theoretical models of eating disorders. What implications does this have for the delivery and provision of clinical services for people with eating disorders?

Introduction

'Eating disorders' is an umbrella term referring to a range of disorders where there is a serious disturbance in eating habits. Two of these disorders, anorexia nervosa and bulimia nervosa\(^1\) will be focused upon within this essay. Anorexia is characterised by an intense fear of becoming fat, despite being seriously underweight. There is a refusal to maintain body weight at a normal level, with food intake being severely restricted. Amenorrhoea also features in post-menarchal females (Wilson, 1999).

The main features of bulimia are recurrent episodes of binge eating, characterised by a lack of control. Compensatory behaviours are engaged in to prevent weight gain, which include self-induced vomiting, excessive exercise, and the use of laxatives or diuretics. The binges and accompanying behaviour must be engaged in at least twice weekly for 3 months for a diagnosis to be made. Similar to anorexia, self-evaluation is excessively linked to body weight and shape (Roth & Fonagy, 1996).

Both of these disorders have been regarded as complex and difficult to treat (Bell, Clare & Thorn, 2001). Anorexia has the highest morbidity rate out of all the psychiatric disorders (Nielsen et al., 1998: cited in Bell et al., 2001), with bulimia being termed 'intractable' by Russell in 1979, although this situation has since changed (Fairburn, 1997). Co-morbid problems such as depression, obsessive-compulsive disorder and personality disorder, as well as serious medical complications, often occur within these individuals (Palmer, 2000).

This essay aims to compare two theoretical models, and the treatments that have arisen from these models, in order to discuss the evidence base relating to the eating disorders of anorexia and bulimia. For the purposes of this essay the theoretical models which will be focused upon are cognitive behavioural and family therapy\(^2\). Anorexia will be discussed first, with details of the two theoretical models and

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\(^1\) The terms anorexia and bulimia will be used in this essay.

\(^2\) The term family therapy, as opposed to systemic, will be used in order to reflect the literature.
associated evidence being provided, prior to the evidence being compared and implications discussed. Bulimia will then be focused upon in a similar manner.

**Anorexia**

*The Cognitive-Behavioural Model*

The cognitive theory used to guide treatment in anorexia was developed by Garner and Bemis in 1982, and was adapted largely from Beck’s 1976 model of the emotional disorders, particularly depression (Cooper, 1997). This theory has been further refined by Garner, Vitousek and Pike (1997), and has been presented in a manual format (Garner et al, 1997). In this model attitudes and beliefs such as “I must be thin” are assigned a causal role in the maintenance of anorexia. The identification of cognitive distortions in the processing and interpretation of events is emphasised, as is the evaluation of automatic thoughts and underlying assumptions. Garner et al. (1997) note this is similar to the cognitive-behavioural model for bulimia, although there are certain alterations to deal with motivational issues and the effects of starvation. Treatment can range from 1-2 years and is divided in to 3 stages as detailed in Table 1.

**Table 1: The 3 stages in the cognitive behavioural model of treatment for anorexia** (Garner et al., 1997)

<table>
<thead>
<tr>
<th>Treatment stage</th>
<th>No. of Sessions</th>
<th>Main elements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage 1</td>
<td>1-8</td>
<td>Building a good therapeutic relationship</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Increasing the motivation for change</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Education about anorexia, medical complications, starvation</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Information on the cognitive-behavioural model of treatment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Prescribing normal eating patterns</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Introducing self-monitoring, and the planning of meals</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Identifying/challenging societal values regarding weight &amp; shape</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Establishing the suitability of involving the family in therapy</td>
</tr>
<tr>
<td>Stage 2</td>
<td>9-16</td>
<td>Continued focus on increasing weight and establishing normal eating patterns</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Cognitive restructuring to alter beliefs related to food and weight</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Reframing any relapses</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Exploring wider issues including relationships</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Involving the family if appropriate</td>
</tr>
<tr>
<td>Stage 3</td>
<td>17-19</td>
<td>Reviewing progress</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Developing strategies for relapse prevention</td>
</tr>
</tbody>
</table>
Fairburn et al. (1999: cited in Wilson, 1999) have offered an alternative account of what maintains anorexia. Instead of concerns with weight and shape, the extreme need to control eating is viewed as the defining feature, with the suggested treatment being targeted primarily towards the individual’s sense of self-control. The author is unaware of any evidence using this particular model for cognitive-behavioural treatment of individuals with anorexia.

_The Cognitive-Behavioural Evidence-Base_

Garner at al. (1997) state there have been several case reports that indicate cognitive-behavioural therapy (CBT), the treatment arising from the cognitive-behavioural model, is effective with this client group, however little other evidence exists, in the form of adequately controlled studies, on the use of CBT for individuals with anorexia.

In one of the few controlled outcome studies conducted, Channon, DeSilva, Hemsely and Perkins (1989: cited in Roth & Fonagy, 1996), compared CBT, behaviour therapy and a control routine out-patient treatment in 24 individuals with anorexia. At 6 and 12 month follow up all 3 groups had increased in weight and made improvements in psychosocial functioning, however no significant differences were found between the treatment groups. Several problems have been found with this study. Palmer (2000) concluded that the time frame was insufficient, with Vitousek (1996) noting that it was substantially shorter than the treatment length specified by Garner and Bemis (1982). Furthermore the sample size was too small for the 3 conditions thus affecting the statistical power of the study, and the cognitive components used did not appear to be synonymous with Garner and Bemis’ guidelines for anorexia (Vitousek, 1996).

Clearly there is a need for further controlled studies in this area to provide further evidence as to the efficacy of CBT for anorexia.

_Family Therapy (FT) Models_

Within this approach emphasis is placed on certain organisational and interactional features within the family that are thought to predispose or maintain an individuals’ eating disorder. Although there are a number of models, such as structural, Milan
systems, and post-Milan, which offer differing views as to the nature of FT and the mechanisms which affect change (Dare & Eisler, 1997), a commonality is the emphasis placed upon the family in the development and resolution of the problem, with causality being regarded as a circular, and not linear process (Eisler, 1995).

One of the most influential models in developing family therapy as a treatment for eating disorders comes from the structural approach and the work of Minuchin et al. (1978: cited in Dare & Eisler, 1997). This, as well as another important model, Milan systems, will be discussed below.

Minuchin et al. (1978) stated that several factors were necessary for the development of anorexia. Firstly the individual is physiologically vulnerable, secondly certain characteristics are evident within the family; overprotectiveness, a lack of conflict resolution, rigidity, and enmeshment. Lastly the individual has a crucial role in conflict avoidance within the family, which acts as an important reinforcer of the individuals’ symptoms (Dare & Eisler, 1997). Within this model the individuals’ symptoms are located within the dysfunctional family structure. Treatment is characterised by changing the way in which the family is organised, through altering dysfunctional patterns of interaction, and enhancing other more appropriate forms. The context of a family meal is used to provide a direct observation of the way in which the dysfunctional patterns have become manifested in the eating problem. Within this the technique of ‘unbalancing’ is used, in which the therapist supports certain members of the family more in order to challenge the prevailing structure. This is exemplified though the therapist supporting the parents more in their attempts to make their offspring eat. The intention is to improve the family organisation, with more appropriate hierarchies and boundaries, so that the structures which are supporting the symptoms will be removed (Dare & Eisler, 1997).

A differing perspective is provided by the Milan systems model. Selvini Palazzoli (1988: cited in Carr 2000b) emphasised certain features as typical within families containing an individual with anorexia: secret alliances between family members, unclear communication, little leadership by parents, and an ethic of self-sacrifice. The view of the family within the Milan systems model is of a rigidly organised
system, with the individuals' symptoms having a powerful homeostatic effect on the system. The aim is to introduce different information into the system to alter the 'family games', that is problem-maintaining interactional patterns, which lead to the alleviation of symptoms. Techniques used include positive connotations to reframe the problem, therapeutic rituals between sessions and circular questioning. A standardised intervention known as the 'invariant prescription', where the parents meet in private away from the home, is also essential. Neutrality of the therapist is important, which differs with the structural approach, and its technique of 'unbalancing' (Carr, 2000b).

Dare & Eisler (1997) note the model of therapy that has been utilised with adolescents with anorexia within the Maudsley trials (which will be discussed in the next section) resembles the structural model more than any other model, although there are some important differences. Similar to the structural approach parents are supported in taking control of the individuals eating and refeeding. However no assumption is made about the way the family is organised in terms of whether or not it is dysfunctional. The evidence for the treatment of anorexia using FT shall now be discussed.

**Family Therapy Evidence-Base**

The early family therapists such as those from the Philadelphia, and Milan groups reported good outcomes in their work (Dare & Eisler, 1997) however they did not conduct any controlled studies, or systematic follow ups to provide further verification as to the efficacy of this approach (Robin, Gilroy & Dennis, 1998). This has led Roth and Fonagy (1996) to refer to the dearth of evidence for anorexia, noting that few comparative trials of psychotherapies exist.

One of the few trials was conducted by Russell, Szmukler, Dare and Eisler (1987), who compared FT with individual supportive therapy in 80 individuals. They found FT to be superior to individual supportive therapy in a subgroup of individuals with anorexia who had an early onset, (before 18 years) and short duration, (less than 3 years) of the disorder. This contrasts with individuals with late onset anorexia and long duration, who faired better with individual supportive therapy. The early onset,
long duration subgroup with anorexia had a poor outcome regardless of the type of
treatment they received.

In a 5-year follow-up study these differences in outcome were still evident (Eisler et
al., 1997), providing a strong argument for using family therapy in adolescents with a
short duration of anorexia. Conversely these findings also suggest that individual
supportive therapy, rather than family therapy, is more appropriate for individuals
with late onset anorexia, with a long duration. Eisler et al. (1997) state this to be the
first psychological treatment trial where positive results have been maintained during
the course of 5 years in anorexia. They note that there were some limitations to the
study such as incomplete follow-up data, and a small sample size. These important
results need replicating (Palmer, 2000).

In a further Maudsley study Le Grange, Eisler, Dare & Russell, (1992: cited in Robin
et al., 1998) compared conjoint family therapy, with family counselling, where
parents were seen independently of the patient. Significant improvements in weight
and attitudes towards eating were found. In spite of expectations to the contrary no
significant differences were discovered between these therapies, suggesting that
seeing the whole family together is not necessary to produce positive outcomes.

Focusing on adults with anorexia, Dare, Eisler, Russell, Treasure and Dodge (2001)
compared the effectiveness of different psychotherapies by randomly assigning 84
adults to one of 4 out-patient treatments: focal psychoanalytic psychotherapy, family
therapy, cognitive analytic therapy, and a control condition involving routine minimal
contact. At one-year follow up the results appeared disappointing with two-thirds of
the participants remaining abnormally underweight. However Dare et al. (2001) did
find focal psychotherapy and family therapy to be more useful in ensuring weight
gain than the control treatment, and concluded that these two therapies are of value in
treating adults with anorexia on an out-patient basis.
**Comparison of the CBT/FT Evidence-Base**

In comparing the evidence base between CBT and FT for individuals with anorexia it is apparent that for both approaches the evidence base is insufficient, although slightly more exists for FT.

Vitousek (1996) provides reasons for this lack of evidence. Firstly there are difficulties in recruiting a sufficient sample as the prevalence of this disorder is low, and those with anorexia are often resistant to treatment. Secondly, the longer course of treatment required might increase the possibility of participant attrition, which could result in a smaller sample size and create problems with randomisation.

Much of evidence base for FT appears to be based on trials that are substantially larger, and more methodologically robust (e.g. Russell et al., 1987) than the trials involving CBT (e.g. Channon et al., 1989). As with much of the evidence, both of these trials are out-patient based with no trials existing to signify the need for in-patient based treatment (Meads et al., 1999: cited in Bell et al., 2001).

One similarity between these 2 theoretical models from which the treatments are derived, is the emphasis placed upon engaging the individual in treatment, and forming a sound therapeutic relationship upon which treatment is hinged. This is deemed to be crucial in the treatment of individuals with anorexia (Palmer, 2000).

In an extensive review Wilson and Fairburn (1998: cited in Carr, 2000a) conclude that family therapy, as well as the individualised form with accompanying family counselling, is effective in treating anorexia. They list certain elements as important in effective treatment, such as engagement of the individual, psycho-education as to the risks associated with starvation, and relapse prevention. The author notes these elements appear to fit comfortably within a FT or CBT approach. However others, such as facilitating the individuals increasing autonomy within the family, seem more FT based.

No studies exist which directly compare FT with CBT in individuals with anorexia. Although the evidence is limited it would appear that for some individuals with
anorexia FT has been shown to be effective in the long-term through controlled trials (Dare & Eisler, 1995). This has implications that will be discussed in the next section.

**Implications**
Currently not enough is known about how best to help individuals with anorexia in clinical practice (Palmer, 2000).

Little strong evidence exists in terms of which therapy is most effective (Department of Health, 2001). However it would seem from the limited evidence base to-date that adolescents with a short duration of anorexia, that is less than 3 years, may have a better outcome with family therapy. Individual therapy of a broadly based nature may be more beneficial for individuals with a late onset of anorexia, that is, after 19 years of age, which has endured for over 3 years (Russell et al., 1987). These findings have been maintained at 5-year follow up, and are therefore encouraging (Eisler et al, 1997). Many individuals however show no improvement as demonstrated in the Dare et al. (2001) study, with approximately one-quarter to one-third of individuals not recovering (Ratnasunya et al., 1991: cited in Bell et al., 2001).

Although family therapy has been shown to be effective in a subset of individuals with anorexia (e.g. Russell et al., 1987; Eisler et al., 1997) it may be difficult to administer in everyday practice. The availability of family therapists with the necessary skills, and time to treat anorexia may be limited in current services (Palmer, 2000). Additionally this intervention may not be possible due to the patient not wanting their family to be involved, or they themselves being resistant to any form of treatment (Dare & Eisler, 1995). Other therapies such as motivational enhancement therapy, which seeks to increase the individuals’ level of motivation, may be necessary in these circumstances (Bell et al., 2001).

The type of provision most appropriate for individuals with anorexia is not altogether clear from the evidence-base. As mentioned no randomised controlled trials (RCTs) exist to demonstrate the need for in-patient treatment, although in everyday practice this forms an essential ingredient in the care of individuals whose life is threatened.
due to their anorexia (Howard et al., 1999: cited in Bell et al., 2001). More research is required to evaluate acceptable and cost-effective alternatives to in-patient treatment such as day-patient treatment (Bell et al., 2001).

From the evidence anorexia appears to take a considerable amount of time to treat. The Russell et al. (1987) study treated individuals for one year, with up to 2 years being recommended using the cognitive behavioural model (Garner et al., 1997). However time frames of up to 6 years have been described in the APA practice guidelines (2000: cited in Bell et al., 2001). Given the type and duration of treatment likely to be beneficial, and the numerous risks involved in terms of morbidity and disability, specialist services are considered necessary in treating individuals with anorexia (Palmer, 2000).

**Bulimia**

_The Cognitive-Behavioural Model_

CBT for bulimia was proposed in 1981 by Fairburn, with detailed treatment manuals emerging in 1985, and 1993 (Fairburn, 1997). The cognitive-behavioural model as described in the current 1993 manual emphasises the crucial role of cognitive and behavioural factors in the maintenance of bulimia (Wilson, Fairburn & Agras, 1997). A central feature relates to concerns about the importance of body weight and shape. Individuals with bulimia judge themselves almost exclusively in terms of their weight and shape, they have what Vitousek and Hollon (1990: cited in Fairburn, 1997) term 'weight-related self-schemata'. Once established these beliefs influence the individual to "engage in stereotypic eating and elimination behaviours ....to process information in accordance with predictable cognitive biases, and eventually, to be affected by the physiological sequelae" (Vitousek, 1996, p.384). A diagrammatic view of the model is shown in Figure 1.
Low self-esteem

Extreme concerns about shape and weight

Strict dieting

Binge-eating

Self-induced vomiting

Figure 1. The Cognitive-Behavioural model of the maintenance of bulimia (Fairburn et al., 1993: cited in Wilson et al., 1997)

One implication of this model is the main focus for treatment should be on beliefs and attitudes about weight which produce the disturbed eating patterns, and not solely on the presenting behaviours of binging and purging (Wilson et al., 1997).

Fairburn (1997) describes the treatment as problem-orientated and relatively short-term, comprising 19 individual out-patient sessions over approximately 20 weeks. It is highly structured, and additive, that is, new procedures are added and remain, building upon one another, as opposed to being introduced and revoked. Treatment comprises 3 stages as detailed in Table 2. Considerable evidence has been generated for the cognitive behavioural approach as a model for treatment in individuals with bulimia, to which attention shall now be turned.

Table 2: The 3 stages in the cognitive behavioural model of treatment for bulimia (Wilson et al., 1997).

<table>
<thead>
<tr>
<th>Treatment stage</th>
<th>No. of Sessions</th>
<th>Main elements</th>
</tr>
</thead>
</table>
| Stage 1         | 1-8             | Formation of a sound therapeutic relationship  
|                 |                 | Psychoeducation regarding the cognitive-behavioural model, body weight regulation, consequences of binge eating/purging  
|                 |                 | Behavioural techniques to replace binge eating/purging with a pattern of regular eating, weekly weighing  
|                 |                 | Self-monitoring through daily food diaries |
| Stage 2         | 9-16            | Further establish healthy eating patterns with particular emphasis on eliminating dieting  
|                 |                 | Cognitive restructuring/problem solving to identify and challenge the thoughts, beliefs and values maintaining the problem |
| Stage 3         | 17-19           | Relapse prevention strategies and maintenance of change e.g. preparing a written plan for use in times of difficulty |
The Cognitive-Behavioural Evidence-Base

CBT is the most researched treatment for bulimia (Robin et al., 1998). Wilson (1999) notes there have been over 20 randomised controlled trials that provide evidence as to its efficacy.

In one particularly illuminating trial Fairburn et al. (1991, 1993: cited in Vitousek, 1996) compared CBT, with behavioural therapy (BT) and interpersonal therapy (IPT) in 75 individuals. Following therapy those individuals who had received IPT had a poorer outcome than those receiving CBT or BT, however at 12 months this situation had dramatically altered with those in the BT group fairing worst in terms of recovery, with those in the IPT group slightly outperforming individuals who received CBT. Fairburn et al. (1995) were able to re-assess 90% of the original cohort by interview on average 5.8 years later, and found the results described above were generally maintained, providing validity for using CBT or IPT in individuals with bulimia.

As well as comparing CBT with other psychotherapies, CBT has been compared against pharmacological interventions (Robin et al., 1998). In a review article Wilson and Fairburn (1998: cited in Wilson, 1999) claim that CBT remains superior to medication in treating bulimia, with the combination of the two significantly more effective than medication alone. CBT has also been used in group studies e.g. Schneider and Agras (1985: cited in Palmer, 2000), however the effectiveness tends to be lower than with individual-based treatment (Palmer, 2000), and a high drop out rate tends to be incurred (Bell et al., 2001).

Further support for the cognitive-behavioural model of bulimia, as described earlier, comes from research that has sought to 'dismantle' the treatment by removing certain procedures which are designed to bring about cognitive change, only to find the effects were attenuated with patients being markedly prone to relapse e.g. Fairburn et al. (1993: cited in Fairburn, 1997).
The faster impact of CBT, against other therapies such as IPT (e.g. Fairburn et al., 1995), as well as its large evidence base, has lead to CBT being regarded as the treatment of choice for bulimia (Agras, Walsh, Fairburn, Wilson & Kraemer, 2000a).

Despite this impressive list of evidence for CBT it seems its effectiveness is limited. Wilson (1997) notes that approximately 50% of individuals cease binging and purging, with the remainder not responding sufficiently, either showing partial or no improvement, following this treatment. Even in Fairburn et al’s (1995) study one in five individuals (19%) still met the DSM IV criteria for bulimia, with 46% retaining an eating disorder of some description. This has prompted research into identifying predictors of likely non-responders to CBT (e.g. Agras et al., 2000b), as well as characteristics of individuals likely to show a quick and sustained response (e.g. Bulik, Sullivan, Carter, McIntosh & Joyce, 1999).

**Family Therapy Models**

There appears to be little literature within FT targeted specifically toward bulimia. Within FT models, eating disorders such as bulimia would be regarded as maintaining certain dysfunctional roles, conflicts or interactional patterns within the system, that is, the family. The family would be a central element in the treatment process (Dare & Eisler, 1997). In order to avoid repetition, the reader is referred to the section on anorexia for further details regarding FT models.

**Family Therapy Evidence-Base**

The evidence base for FT with individuals with bulimia is severely limited (Palmer, 2000).

Two of the Maudsley studies have included individuals with bulimia in their sample (e.g. Russell et al., 1987; Eisler et al., 1997), when comparing family therapy to individual supportive therapy. Both studies reported those individuals with bulimia to have a poor outcome with little change in symptoms and weight gain irrespective of which treatment they received.
A more promising finding comes from Dodge, Hodes, Eisler, and Dare (1995: cited in Robin et al., 1998) who explored the use of FT in the treatment of 8 adolescents with bulimia. Following FT they found improvement on measures of attitudes towards eating, and frequency of harming behaviours such as self-induced vomiting and laxative abuse. These results suggest, that for some individuals with bulimia FT could prove beneficial, however it should be noted that the sample size was extremely small in this study, there was no random assignment to another treatment or control group, and there was little follow up (Robin et al., 1998). These factors need to be rectified in further studies before any firm conclusions can be made.

Comparison of the CBT/FT Evidence-Base
Considering the evidence base it appears that substantially more evidence exists for CBT than FT in individuals with bulimia. Furthermore the evidence for CBT is at a more advanced stage with, for example, predictors being examined for those individuals least likely to respond to treatment e.g. Agras et al. (2000b). No direct comparisons of CBT and FT are apparent for bulimia in the research literature. Such a study would prove illuminating.

Jarman and Walsh (1999) give caution to the diversity of measures and methods employed in outcome studies. The author notes that it is difficult to compare these two approaches as the methods used are extremely different, preventing a like with like comparison. For example within the Maudsley studies described (e.g. Russell et al., 1987; Eisler et al., 1997) individuals with bulimia were used who had been previously hospitalised due to their low weight and severe ill-health. This contrasts greatly with the mainstay of individuals in the CBT studies, who are of normal weight and treated on an out-patient basis.

One similarity is that RCTs have been used to establish the efficacy of CBT and FT within bulimia. This method has been criticised for excluding individuals with a poor prognosis, with Mitchell, Hoberman, Peterson, Mussell and Pyle (1996) suggesting the populations studied for bulimia only represent a specific subset of individuals, thereby limiting the generalisability of the results. Wilson (1998) however views
such criticisms as unfounded with RCTs frequently including individuals with numerous problems and differing degrees of disturbance.

One important difference in the evidence base is that more follow up data exists for CBT than FT. Roth and Fonagy (1996) suggest such data is likely to be critical to any conclusions regarding the effectiveness of different treatments, as evidenced clearly through Fairburn et al's (1995) study.

At present the exclusive use of family therapy for individuals with bulimia, is thought to be insufficient on its own (Robin et al., 1998). CBT however is regarded as the treatment of choice for individuals with bulimia (Agras et al., 2000a). The implications of this will now be explored.

Implications
Using CBT in a manualised format for individuals with bulimia has implications for services. It is a specialist treatment, which is demanding and labour-intensive, requiring approximately 20 therapy sessions over a 4-6 month duration (Wilson et al., 1997). Therefore the cost in terms of time and appropriate resources is fairly high, with appropriately trained therapists possibly being unavailable in many clinical services (Palmer, 2000).

In an attempt to reduce some of these costs, the idea of stepped care has been suggested (Fairburn & Peveler, 1990: cited in Palmer, 2000). This involves treatments being offered in a hierarchical sequence, with briefer and cheaper interventions being provided before more time-consuming and expensive treatments, such as manual-based CBT (Palmer, 2000). These simpler interventions are now being explored, and include the use of guided self-help, where individuals receive restricted input from a therapist whilst they use a cognitive-behavioural self-help manual. The results of one study were particularly promising (Cooper, Coker & Fleming, 1994). Other interventions include condensing the CBT manual and administering it in primary care by non-specialists such as nurses (Waller et al., 1996). These methods, as well as group psycho-education programmes, appear to be effective in a significant group of individuals with bulimia (Wilson, 1999).
author considers the long-term follow up of the individuals involved to be important in establishing these methods true validity.

Although manual based CBT is regarded as being the treatment of choice for bulimia it is not effective in all cases, as certain co-morbid problems such as psychotic states, substance abuse, severe depression and suicidal ideation may prevent the individual from fully engaging in treatment (Wilson et al., 1997). Another reason is that the treatment itself is not effectively implemented, with many therapists straying from the manual (Fairburn, 1997). Palmer (2000) notes however that within clinical services many therapists who treat individuals with bulimia do not use manual-based treatment. This could be due to cost, but also that treatment manuals may be thought of as restrictive to the therapists' autonomy, and so reduce the effectiveness of treatment (Wilson, 1998). Wilson et al. (1997) argue against this, noting the limitations of clinical judgement, and emphasise the need to employ treatments from empirically based research, namely in this case manual based CBT.

There is already discussion around how to make these manuals more therapist-friendly, aiding dissemination, and flexibility amongst patients with bulimia. Wilson (1999) suggests that manuals of the future will include different modules that can be selected and applied to individuals who have different bulimia profiles. There is also the potential to identify non-responders quicker and modify treatment (Wilson, 1998), for example one study concluded that individuals who failed to achieve a reduction in purging of 70% by session 6 were less likely to respond to CBT, thus allowing early use of alternative treatments (Agras et al., 2000b). More predictors of which patients are most appropriate to treatment is required, which would be an important advance clinically (Wilson et al., 1997).

The question remains as to what clinicians might offer if CBT does not seem to be effective. Palmer (2000) suggests that there should be a break in treatment following uneventful therapy, as occasionally people change without treatment, or the effects may be delayed, as was the case in the Fairburn et al. (1995) treatment trial. Other treatments such as IPT could be used, however adapting and expanding the CBT treatment to encompass issues such as self-esteem, rather than replacing it with
something else, may prove more fruitful (Fairburn, 1997). It is important to be aware that some individuals with bulimia may not recover irrespective of the amount of treatment they receive from clinicians, suggesting their bulimia may well be intractable (Wilson, 1997). This can be demonstrated through Fairburn et al.'s (1995) follow up which discovered that two thirds of those individuals who still had an eating disorder on average 5.8 years later had received further psychiatric treatments, all to no avail (Wilson, 1997). These individuals pose their own particular problems for clinical services.

Conclusion

Within this essay the evidence base for two different theoretical models: cognitive-behavioural and family therapy has been compared in conjunction with the eating disorders of anorexia and bulimia, and the implications of this discussed.

It would seem that the evidence base varies considerably according to the theoretical model and eating disorder concerned. With bulimia there is a strong evidence base arising from the theoretical cognitive behavioural model, which applies CBT in practice. The findings suggest CBT is a valuable treatment in bulimia, with it being regarded as the treatment of choice (e.g. Agras et al., 2000a). As mentioned FT does not form one unified approach, and thus there are several differing models within FT upon which treatment is based. Within this essay structural and Milan systems models have been focused upon. Little evidence exists for this in bulimia. This contrasts with anorexia, for which there appears to be a larger FT evidence base, especially with regard to onset within adolescence. The evidence is less clear-cut for adults, with some form of individual therapy being regarded as useful (Bell et al., 2001).

The evidence has certain implications for services, with both disorders utilising many resources due to the treatment duration and the amount of specialist skills required. Further methodologically sound research is required to address the gaps in the evidence base arising from the 2 theoretical models described, in order to effectively treat individuals with these complex eating disorders.
References


People with Learning Disabilities Essay

Critically review the current status of the assessment and treatment of dementia in adults with learning disabilities.

July 2002
Year 1
Critically review the current status of the assessment and treatment of dementia in adults with learning disabilities.

Introduction
It is estimated that approximately two percent of the United Kingdom population have what is classed as a 'learning disability' (Thompson, 1999). Although several definitions exist, they all essentially relate to 'a significant impairment of intelligence and social functioning acquired before adulthood' (Department of Health, 1998; cited in the British Psychological Society, 2001, p20). Due to improvements in living conditions, as well as medical advances, the life expectancy of adults with a learning disability is increasing (Janicki, Ackerman & Jacobson, 1985; cited in Whitehouse, Chamberlain & Tunna, 2000), which means that so too are associated problems of ageing, such as dementia. Dementia can be thought of as an umbrella term, referring to a group of disorders in which there is 'an acquired loss of intellectual ability that occurs over a long period of time and affects many areas of functioning (Williams, 1995; cited in Dalton & Janicki, 1999, p6). The most common form is considered to be Alzheimer's disease (Thompson, 1999), which can be defined as 'a progressive, neurodegenerative disease characterized by loss of function and death of nerve cells in several areas of the brain leading to a loss of cognitive function such as memory and language' (Janicki & Dalton, 1999, p448).

This essay aims to critically review the present day status of the assessment and resulting treatment which adults with a learning disability and dementia receive. However due to the almost exclusive focus on Alzheimer's disease within the literature, other forms of dementia, such as multi-infarct dementia, will not be focused upon here. Furthermore in discussing adults with a learning disability this essay will particularly feature adults with Down's syndrome, due to their heightened risk of developing Alzheimer's disease (Turk, Dodd & Christmas, 2001). Down's syndrome is a particular form of learning disability characterized by an extra gene on chromosome 21 (Thompson, 1999). For the purposes of this essay in order to set the context, prevalence rates, symptoms and diagnostic issues will be briefly discussed, prior to reviewing the current status of assessment and treatment practices.
Prevalence of dementia

Within the literature it is generally considered that virtually all adults with Down's syndrome over the age of 40 years develop the neuropathological signs characteristic of Alzheimer's disease (Zigman, Schupf, Haverman & Silverman, 1997), such as amyloid plaques and neurofibrillary tangles (Bullock, 2002), although they may not necessarily go on to develop the disease (Zigman et al., 1997). The only risk factors which have been firmly established for dementia in adults with a learning disability are age and Down's syndrome, although many others have been cited (Dalton & Janicki, 1999). For adults with learning disabilities of other aetiologies, these neuropathological signs are shown considerably later, that is, after 65 years of age (Zigman et al., 1997). Few studies have examined the prevalence rates of Alzheimer's disease in individuals with learning disabilities who do not have Down's syndrome, in contrast many studies have attempted to gauge the prevalence of dementia in adults with Down's syndrome (Zigman et al., 1997). Findings have varied widely for example Lai and Williams (1989; cited in Holland, 1999) reported 55% of 50-59 year olds with Alzheimer-type dementia, which rose to 75% in individuals aged 60 years and above. Prasher's (1995; cited in Holland, 1999) figures were lower, and this study found an average age of onset of 54 years with average duration to death of 4.6 years, which is considerably quicker than the general population (Kerr, 1997). Zigman et al. (1997) found the prevalence figures between studies have ranged from less than 10% to in excess of 75%, and attributes these differences to variations in assessment procedures, diagnostic criteria and sampling techniques, noting the use of non-randomised samples and cross-sectional designs. Thus it would seem that the extent of adults with a learning disability needing assessment and treatment for dementia is not fully known.

Symptoms

The symptoms associated with dementia are multiple and arise at differing points during its course (Kerr, 1997). The use of 3 stages detailing symptoms associated with early, middle and late stages has been used (Janicki, Heller, Seltzer, & Hogg, 1996). The way in which the symptoms are expressed, and the point at which they occur, is likely to vary between individuals with a learning disability (Janicki et al., 1996).
Although not intended to be prescriptive, some of the characteristics which may be associated with these stages can be found in Table 1.

**Table 1: Symptoms characteristic of the dementia stages (Janicki et al., 1996)**

<table>
<thead>
<tr>
<th>Stage</th>
<th>Typical characteristics</th>
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<tbody>
<tr>
<td>Early</td>
<td>Gradual onset of short-term memory loss, word finding difficulties, slowness in movement, loss of interest in activities or routines, changes in behaviour</td>
</tr>
<tr>
<td>Middle</td>
<td>Diminishing communication and self-care skills, disorientation to time, person and place, further changes in personality and social behaviour, onset of seizures and further memory loss</td>
</tr>
<tr>
<td>Late</td>
<td>Significant loss of skills e.g. eating, drinking, walking, use of language, short and long-term memory, balance, bowel and bladder functioning, complete lack of awareness of surroundings</td>
</tr>
</tbody>
</table>

**Diagnosing dementia**

The diagnosis of dementia in adults with a learning disability is somewhat problematic, given the lack of standardized criteria (Aylward, Burt, Thorpe, Lai, & Dalton, 1997). Current diagnostic systems such as the Diagnostic and Statistical Manual of Mental Disorders (DSM IV; American Psychiatric Association, 1994; cited in Aylward et al., 1997), and the International Classification of Diseases (ICD 10; World Health Organisation, 1992; cited in Aylward et al., 1997) although detailing learning disability and dementia separately, do not do so in combination (Aylward et al., 1997). The validity of the DSM IV criteria for people with a learning disability is queried by Oliver (1999), with preference being placed upon using ICD 10 as this emphasizes non cognitive aspects of dementia such as irritability and apathy which are regarded as being amongst the first signs to be manifested in individuals with a learning disability, particularly in those with limited verbal skills (Aylward et al., 1997). In 1997, on behalf of an international working group, Aylward et al. proposed a set of diagnostic criteria for dementia in adults with a learning disability. The criteria included evidence of declines in memory, in other cognitive abilities such as planning and expressive and receptive language, and changes in emotional control or social behaviour. All criteria needed to be met, with other factors excluded, and be present for at least 6 months prior to diagnosis being made. Only if there was evidence of a gradual onset with continuing cognitive decline would a diagnosis of Alzheimer’s disease be warranted (Aylward et al., 1997). Furthermore depending on the number and type of symptoms present a distinction between a diagnosis of
possible Alzheimer's disease as opposed to probable Alzheimer's disease was suggested (Aylward et al., 1997). The lack of standardized diagnostic criteria may make the assessment of dementia problematic. The issue of assessment will now be explored.

**Assessment**
The special considerations of assessing adults with a learning disability, and suspected dementia, will first be discussed before moving on to the measures available, namely those used directly with the individual, and indirect measures referred to here as informant-based scales. Finally the differing approaches to assessment, that of retrospective or prospective, will be reviewed.

**Special Considerations**
Assessing adults with a learning disability for dementia is more complicated and time consuming than for the general population (Kerr, 1997). There are several reasons for this and these will be discussed here. Unlike the general population, adults with a learning disability have pre-existing cognitive impairments, therefore the extent of these needs to be determined, meaning that a baseline level of functioning is first required (Oliver, 1999). However baseline levels are more heterogeneous than the general population, and are thus more difficult to reliably establish given the number of factors involved, such as the variability in degree of learning disability, the cognitive, physical and sensory impairments, the presence of medical conditions such as epilepsy, as well as behaviours typical for the individual, and all these factors need to be taken into account in the assessment (Burt & Aylward, 1999). Furthermore in assessing for a diagnosis of dementia a change is required from this baseline, therefore a longitudinal as opposed to a one-off assessment is necessary (Burt & Aylward, 1999). Given the complex nature of the assessment and the multiple needs involved it is thought this assessment should be multi-disciplinary (Kerr, 1997).

When assessing for dementia other possible causes for any perceived decline need to be excluded first (Aylward et al., 1997), some of which are listed in Table 2. This can be very difficult to do. For example many of the symptoms which accompany depression are also associated with Alzheimer's disease, making it hard to disentangle
the two conditions, which could in fact exist co-morbidly (Aylward et al., 1997). Certain features such as hypothyroidism and auditory impairments are particularly prevalent in adults with Down’s syndrome (Kerr, 1997). Other features associated in people with a learning disability such as limited speech, poor comprehension and a tendency to acquiesce may further confound the assessment (Thompson, 1999).

Table 2: Factors to exclude when considering dementia (Holland, 1999)

<table>
<thead>
<tr>
<th>Factors</th>
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<tbody>
<tr>
<td>Depression</td>
</tr>
<tr>
<td>Life events e.g. bereavement, residential change</td>
</tr>
<tr>
<td>Physical illness</td>
</tr>
<tr>
<td>Sensory impairments e.g. hearing, vision</td>
</tr>
<tr>
<td>Thyroid disorder</td>
</tr>
<tr>
<td>Deterioration arising from medication e.g. folic acid abnormalities from anti-convulsants</td>
</tr>
</tbody>
</table>

For dementia to be suspected changes from baseline need to be greater than those associated with normal ageing (Burt & Aylward, 1999). This is a further problem, as it would seem that what constitutes normal ageing in adults with Down’s syndrome has not been firmly established (Thompson, 1999). In addition the profile of decline, although regarded as similar to that experienced by the general population, may merit further investigation (Oliver, 1999), as differences have been noted, for Burt et al. (1998) found one individual displayed an early expressive language decline, whilst another demonstrated early declines in memory.

**Direct assessment of the individual**

In assessing for dementia in adults with a learning disability, reliable and valid measures are required. However it would seem that many of the assessments which have been used have not been validated on this population, and thus may not be sensitive enough to detect subtle changes as they occur (McCallion, 1999). For example in assessing for dementia, cognitive tests such as the Middlesex Elderly Assessment of Mental State (Goldberg, 1989; cited in Thompson, 1999) have been used. A few assessments have been adapted for this client group such as the Test for Severe Impairment (Albert & Cohen, 1992; cited in Deb & Braganza, 1999) and the McCarthy Verbal Fluency test (McCarthy, 1972, cited in Deb & Braganza, 1999). Whereas other tests, although not specific to dementia, have been regarded as
providing useful information on a range of cognitive abilities e.g. the Leiter International Performance Scale (Leiter, 1974; cited in Burt & Aylward, 1999), and the Wechsler Adult Intelligence Scale-Third Edition, (Wechsler, 1999; cited in Burt & Aylward, 1999). It would seem that in assessing dementia in adults with a learning disability, several tests are required as one measure alone does not sufficiently cover the range of cognitive abilities associated with dementia (Hon, Huppert, Holland, & Watson, 1999). Furthermore there appears to have been little consensus regarding the most appropriate assessments to use in adults with a learning disability when dementia is suspected, and a lack of standardised measures for this population is clearly evident (Oliver, 1999).

There is a need for new tests to be developed for use in this population, as well as the adaptation of existing tests (Oliver, 1999). Attempts have been made to find tests regarded as useful in assessing areas of cognitive functioning known to decline with dementia, for example, Hon et al. (1999) used the Cambridge Cognitive Examination (CAMCOG), a neuropsychological test designed for older adults without a learning disability, in a population based sample of 74 individuals with Down’s syndrome. They concluded that with minor modifications it would prove to be a useful test for individuals with a mild to moderate learning disability. However it was not applicable to all individuals such as those with a severe learning disability, or those with severe sensory impairments given their inability to score above the floor level of the test. Oliver (1999) notes that the possibility of obtaining a ‘floor effect’, that is scoring at the bottom of the assessment is a particular problem for adults with a profound or severe learning disability, with this lower limit prohibiting an indication of their true impairments. Furthermore such measures would not be useful in detecting a decline in follow-up assessments, which poses a problem given that longitudinal assessment is an ‘absolute necessity’ (Burt & Aylward, 1999, p144) in the detection of dementia. The converse of floor effects, that of ceiling effects, are also a problematic feature as they prohibit an indication of the individuals’ true abilities due to an upper limit in the assessment tool (Thompson, 1999). Due to the difficulties inherent in these assessments there is a danger that a false positive or false negative diagnosis could be made, given that no ‘gold standard’ exists to which assessments can be compared against (Oliver, 1999).
A further problem with neuropsychological tests seems to be that it is not fully known as to what constitutes a significant fall off in the test scores, that is the number of points which need to have been lost, in order for a diagnosis of dementia to be justified (Aylward et al., 1997). In addition, any declines obtained in a cognitive assessment need to be substantiated by a change in everyday functioning in order to be clinically meaningful (Burt & Aylward, 1999), however this presents problems, as for instance, some individuals may live in relatively sheltered environments and be presented with little daily challenges and stimulation. This makes it difficult to for changes to be detected in these individuals due to limited demands placed upon them. Carers may also adapt the environment and so successfully mask any deficits (Oliver, 1999).

In reviewing the literature it would seem that studies have employed different neuropsychological batteries e.g. Crayton et al., 1998; Burt et al., 1998. They have also used adults with differing severities of learning disability (Hon et al., 1999) and employed less than ideal designs such as cross-sectional designs, which have been criticised (Zigman et al., 1997). Consequently more studies are required which utilise longitudinal designs in the assessment of adults with a learning disability, to enable individuals to act as their own control (Burt et al., 1998).

Certain strategies have been suggested as a means of improving the reliability and validity of assessment measures. These include employing tests which minimize verbal instructions, as some individuals may have limited or no speech (Crayton, Oliver, Holland, Bradbury, & Hall, 1998), using training procedures (Crayton et al., 1998), as well as combining the tests with other techniques, such as computerized axial tomography scans which may help in aiding the detection of any deterioration (Thompson, 1999). Information from other sources, such as carers and family members may also be sought, to which attention shall now be turned.

**Informant-based measures**

Due to the difficulties with cognitive assessments greater reliance has been placed on informant based scales (Oliver, 1999), examples of which are the Dementia Questionnaire for persons with Mental Retardation (DMR; Evenhuis, 1992; cited in
Deb & Braganza, 1999), and the Dementia Scale for Down’s Syndrome (DSDS; Gedye, 1995 cited in Deb & Braganza, 1999) which both cover cognitive and daily living skills. Other measures include the Reiss Screen for Maladaptive Behaviour (Reiss, 1987 cited in Aylward et al., 1997) which screens for signs of psychopathology (Aylward et al., 1997), and the Vineland Adaptive Behaviour Scale (Sparrow, Balla & Cicchetti, 1984; cited in Burt et al. 1998), which provides information on social functioning. Similar to the cognitive assessments described above, the DMR and DSDS do not allow for clinical differentiation of different types of dementia such as frontal-lobe type dementia or Lewy body dementia (Deb & Braganza, 1999), however they are a non-intrusive means of acquiring information, which is a distinct advantage over direct formal assessment (Sims, 2002). Furthermore the DMR includes an item for orientation (Prasher, 1997), which is important to assess given that temporal or spatial disorientation may be more apparent initially than other cognitive deficits (Aylward et al., 1997). These measures necessitate completion by people who know the individual well. However this can often be problematic, as due to the high rate of staff turnover which generally occurs in residential settings, it may be difficult to identify staff who have known the individual for long enough to provide a valid and reliable assessment (Oliver, 1999).

Consequently carers may not recognize important changes when they occur, especially in the early stages when signs may be subtle, and attribute these instead to the individuals learning disability, which results in the dementia being ‘overshadowed’, and precludes appropriate referral, care and treatment (Oliver, 1999). The converse of this is also possible with all behaviours being attributed to dementia whilst other more treatable conditions such as depression are overlooked (Oliver, 1999). Aylward et al. (1997) have therefore suggested that ideally multiple informants would be used, consisting of family and non-family members, who know the individual well from a range of settings. Cultural factors also need to be considered (Aylward et al., 1997) as this may affect the way an individual with a learning disability presents.

In light of the above it has been recommended that the direct administration of neuropsychological tests and informant-based measures are both used in assessing
adults with a learning disability for dementia (Aylward et al., 1997). In accordance with this Burt and Aylward (2000), on behalf of an international working group, have recently proposed a battery of tests for use in the diagnosis of dementia, which encompasses both direct assessment of the individual and informant-based scales. They recommend the longitudinal use of this battery with a baseline being obtained in adults with Down’s syndrome prior to 40 years of age, and adults with other learning disabilities before the age of 50, and consider its international use will generate information to help differentiate changes associated with dementia to that of normal ageing. The author notes that a useful consideration of the battery is that it is applicable to individuals ranging from a mild to a profound level of learning disability, it is relatively quick to administer, and it assesses a variety of skills. However the availability of some of the recommended items, of which there are many, may be somewhat limited given the current resource levels within the NHS.

**Retrospective verses prospective assessment**

Assessment of dementia can take the form of a retrospective or prospective approach (Sims, 2002). A retrospective assessment would involve comparing any previous cognitive and functional assessments, as well as historical data held in the notes concerning personal, family and psychosocial background with information relating to current day cognitive and adaptive functioning (Sims, 2002). Processes described earlier, such as excluding other conditions first, need to occur. At present a diagnosis of dementia in adults with a learning disability tends to occur through this approach (Burt & Aylward, 2000). However, this method has several weaknesses. As well as problems associated with initial referral and carers accounts mentioned earlier, much of the information held might be unrelated to detecting specific clinical signs of dementia, for as Oliver (1999) notes, IQ scores may be used to assess global decline, even though these scores are not specific to dementia, and are not sensitive to early subtle changes in functioning. Oliver (1999) gives caution to this approach due to issues of reliability, and also queries how ethical this approach is when a heightened risk is known to exist for certain individuals in developing dementia.

Consequently a prospective approach is increasingly being recommended as the method of choice, especially for adults with Down’s syndrome due to their high risk
of developing dementia (Turk et al., 2001). A prospective approach would entail a baseline of social and cognitive functioning being obtained at an early age prior to the symptoms of dementia occurring, such as by 30 years, with repeated assessments occurring regularly and at more frequent intervals with advancing age (Turk et al., 2001). This approach is time-consuming, and requires substantial resources due to re-assessments (Oliver, 1999). In discussing the ethics of prospective assessment Sims (2002) notes that gaining informed consent could potentially cause distress in some individuals and their carers. Furthermore carefully collected baseline data could become meaningless if the service introduces new assessment tools (Sims, 2002). On the plus side this approach could lead to early detection of dementia which is important, as well as the implementation of appropriate treatments, as detailed in the next section, all of which will have a positive effect on the individuals’ quality of life (Sims, 2002). Swifter exclusion of dementia may also occur, and at a service-level, greater information would be generated as to current and future numbers of adults with dementia, thereby aiding in the planning of an appropriate needs-led service (Sims, 2002). This would allow appropriate treatments to be offered, to which consideration shall now be given.

**Treatment**

The term treatment is perhaps a misnomer, as Alzheimer’s disease is a degenerative condition and currently there is no cure (Dalton & Janicki, 1999). However improvements in functioning in adults with a learning disability and dementia may occur if co-morbid conditions such as depression are treated (Burt et al., 1998). Generally though interventions have been targeted around compensating for the individuals deteriorating abilities and maintaining their quality of life as much as possible whilst preserving dignity and self-respect (Janicki et al., 1996). In discussing treatment, guidelines which have been suggested will first be described prior to the current status of direct and indirect forms of intervention being reviewed.

**Practice guidelines**

Practice guidelines have been developed for the care management of individuals with Alzheimer’s disease and a learning disability (Janicki et al., 1996). These stress the need for regular documentation and the provision of treatments appropriate to the
individual at their particular stage of illness. The principles involved are centred around preserving and maximizing the person's functioning, employing appropriate supports and interventions to the stage of dementia, and utilizing a multi-disciplinary and multi-agency approach. Care practices associated with the different stages of dementia are detailed in Table 3. The author has found few studies concerning the care practices of adults with a learning disability and dementia.

**Table 3: Possible interventions for care management (Janicki et al., 1996)**

<table>
<thead>
<tr>
<th>Stage</th>
<th>Intervention</th>
</tr>
</thead>
</table>
| Early | Simplify the environment to ensure safety, continuation of functioning & use of skills  
Provide supports to meet changing needs e.g. activity level  
Modify communication e.g. use short explicit instructions, cues and verbal prompts |
| Middle | Further supports e.g. to assist with personal care, reduce agitation,  
Maintain physical health, appropriate nutrition, safety  
Make physical adaptations to the home environment  
Regularly review all aspects of care and future planning  
Work with and support families and carers e.g. respite care, educate & inform |
| Late | Provision of 24-hr nursing care and supervision  
Greater emphasis on medical management to prevent infections and other conditions e.g. pressure sores,  
Further support to families and carers re providing terminal care |

**Direct interventions**

Forms of treatment which have been regarded as beneficial include reality orientation, and reminiscence therapy (Hutchinson, 1999; cited in Sims, 2002). Reality orientation involves orientating the individual to their environment, such as the day or place they are currently in. This entails adapting communication to encompass more visual cues such as pictures and symbols as well as colours, and using signing systems previously familiar to the individual such as Makaton (Kerr, 1997). Reminiscence therapy conversely involves remembering the past, and may consist of listening to music which is meaningful to the individual, as well as visiting old familiar places. A life story book which comprises key information and photos from the individual's life may also be used (Kerr, 1997). Few studies appear to have been conducted using these methods on adults with a learning disability and dementia. These methods have typically been employed in older adult services, and the need to work more closely with such agencies has been highlighted in a recent white paper (Department of Health, 2001).
Other treatments are also emerging for Alzheimer's disease, namely medications which have been found to slow the rate of cognitive decline (Turk et al., 2001). These drugs inhibit the enzyme acetylcholinesterase, and thereby enhance the cholinergic neurons and neurotransmitter acetylcholine (Bullock, 2002). Cholinergic deficits are known to be associated with social and cognitive impairments in Alzheimer's disease (Kishnani et al., 1999). Guidance on the use of certain acetylcholinesterase inhibitor drugs such as Donepezil, Rivastigmine and Galantamine have been issued by the National Institute for Clinical Excellence (NICE, 2001; cited in Bullock, 2002) in treating Alzheimer's disease. One small scale study used donepezil in 4 adults with Down's syndrome, 2 of whom had dementia, and reported improvements in areas such as expressive language, and attention (Kishnani et al., 1999). The numbers involved in this study makes it difficult to draw any firm conclusions, and a larger randomized placebo-controlled trial of this medication has been recommended (Kishnani et al., 1999). Arshad, Sridharan and Brown (2001) note that the NICE guidelines do not extend to people with a learning disability, and query the impact of this omission on the prescription of these drugs for adults with a learning disability and Alzheimer's disease. However the issue remains that in order to establish the efficacy of this form of treatment reliable and valid measures are required in order to document the course of changes as they occur (Devenny, Krinsky-McHale, Sersen, & Silverman, 2000).

**Indirect interventions**

One indirect intervention is training and education for carers, as well as professionals, which is greatly needed (Turk et al, 2001). In one small scale study Whitehouse et al. (2000) assessed 21 care staff concerning their knowledge of issues associated with ageing in adults with learning disabilities. They found that care staff had limited knowledge regarding the effects of ageing, in particular dementia, and reported forgetfulness as the first sign they would expect to see if someone had this condition. However, as discussed earlier, emotional and behavioural changes may be the first changes to be manifested (Lai & Williams, 1989; cited in Aylward et al., 1997). Whitehouse et al. (2001) concluded that care staff would have difficulties in noticing changes which could be indicative of dementia due to their limited knowledge base. The author considers that there is clearly a need for larger studies to be conducted on
this issue, as well as training and education being implemented, as treatments cannot be offered if individuals are not first identified.

In reviewing treatments consideration needs to be given to the current system in which they are offered, for this appears to be in need of significant change. It is apparent that the prevailing model of care for adults with a learning disability, that of developing skills and independence, is not appropriate for ageing adults with a learning disability and dementia (McCallion, 1999). As ageing individuals with a learning disability, including those with Down’s syndrome, are a relatively new group it would seem that services are not yet equipped to deal with their needs. Indeed there is a need for services to plan ahead to ensure more suitable provision in terms of residential and respite care as well as day services (Turk et al., 2001). It would seem that a more appropriate model of care would be maintaining skills (McCallion, 1999). In line with this, seven statements known as the Edinburgh Principles, have recently been proposed which detail the needs and rights of individuals with a learning disability and dementia as well as the practices which services, governments and organizations are recommended to adopt (Wilkinson & Janicki, 2002). This is a significant step, however it is not known to what extent these will be taken on board given the constraints of resources, time and the difficulties in bringing different systems together.

Conclusion

Within this essay the current status of the assessment and treatment of adults with a learning disability and dementia has been reviewed. Due to the increase in life expectancy in individuals with a learning disability dementia is a relatively new problem, and it would seem that much research, using appropriate methodologies, needs to be conducted in this area.

As mentioned earlier, it is not clear how many adults with a learning disability are affected with dementia, particularly Alzheimer’s disease, due to the widely varying prevalence rates (Zigman et al., 1997). Thus the extent of need is not yet known. The particular difficulties in assessing people with a learning disability for dementia, such as accurately establishing a baseline, have been highlighted, and these problems are
compounded further by the lack of standardized diagnostic criteria and assessment measures (Aylward et al., 1997). Many of the assessments used have not been developed for this client group, which has created problems e.g. floor effects, and has called into question the reliability and validity of these assessments (Oliver, 1999). This charge has also been levied at informant-based measures (Oliver, 1999), and the combination of direct and indirect assessments has been recommended (Aylward et al., 1997). Another recommendation is the adoption of a prospective approach to assessing adults with Down’s syndrome, who are known to be at high risk of developing dementia (Turk et al., 2001), to facilitate early and appropriate support and care.

Although the importance of early detection has been detailed in the literature little exists on treatment for adults with a learning disability. Practice guidelines have been developed for care management (Janicki et al., 1996), although how these have been translated into everyday practice is not known. However carer knowledge is one area which is likely to need enhancing (Whitehouse et al., 2001). Several recommendations have recently been made as to the way in which services should work to support people with a learning disability and dementia (Wilkinson & Janicki, 2002). These appear to necessitate much change, resources and time. Given the factors detailed above it would seem that many challenges lie ahead in the assessment and treatment of adults with a learning disability and dementia.
References


Children, Adolescents & Families Essay

“Early intervention works”. Critically discuss the evidence for the effectiveness of early intervention approaches for behavioural problems.

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Introduction

Blackman (2002) asserts that “asking whether early intervention works is like asking 'Is food good for you?’” (p.14). The broadness of this question is rather apparent. Indeed early intervention is somewhat broad, being as it is an umbrella term, encompassing many different approaches (McCollum, 2002). As well as the different terms used to conceptualise early intervention approaches, differences exist at what point intervention occurs, that is how early on it happens. This is evidenced through for example 'primary prevention' which involves intervening when certain risk factors are present in the absence of any symptoms and 'secondary prevention', where intervention takes place when problems are at a sub-clinical level (Fonagy, Target, Cottrell & Phillips, 2000). Both of these appear to equate to 'early intervention'. In discussing early intervention approaches parent training programmes will be predominately focused upon, due to parent training being one of the most extensively evaluated treatments for behavioural problems in children (Golding, 2000). Child training programmes will also be included. These two programmes constitute the early intervention approaches focused on in the context of this essay. Furthermore this essay will primarily concern itself with children aged between 3-8 years, that is from the pre-school to primary school period, given that these are the ages most relevant to the afore-mentioned programmes. This essay will therefore seek to define the nature of behavioural problems in children and the long-term risk factors associated with them, before discussing and subsequently evaluating the evidence for the effectiveness of parent training programmes, as well as child training programmes.

Behavioural problems

It is not unusual for parents to show concern regarding their child’s behaviour during the pre-school years. Indeed much of the behaviour may be developmentally appropriate and somewhat transitory and therefore not constitute a significant problem (Douglas, 1998). Indeed it is often thought that children will grow out of their problems (Webster-Stratton, 1997). However many studies have found that this is not
the case, for example Stevenson, Richman and Graham (1985; cited in Sutton, 1992) discovered that the majority of children who displayed behavioural problems at age 3 still had them at 8 years, suggesting that these problems tended to persist over time. Behavioural problems have been classified into internalising behaviours such as withdrawal and anxiety and externalising behaviours, which are more relevant to this essay and include aggression and non-compliance (Achenbach, Edelbrock & Howell, 1987; cited in Douglas, 1998). Depending on factors such as age of onset, nature, severity and duration, externalising behaviours may fall under the diagnostic label of conduct disorder, oppositional defiant disorder or attention deficit hyperactivity disorder (Diagnostic & Statistical Manual of Mental Disorders-Forth Edition (DSM IV); American Psychiatric Association (APA), 1994). Conduct disorder has been found to be the commonest psychiatric disorder of childhood, occurring within 7% of boys and 3% of girls (Meltzer, Gatward, Goodman & Ford, 2000; cited in Scott, Knapp, Henderson, & Maughan, 2001a). Indeed it is the commonest reason for referral to child mental health services within the UK, comprising 30%-40% of all referrals made (Audit Commission, 1999; cited in Scott, Spender, Doolan, Jacobs, & Aspland, 2001b), and the prevalence of this problem is increasing (Herbert, 1985). Typical behaviours include tantrums, disobeying rules, fighting, lying, stealing and destructiveness (Scott, 1998). In describing these behaviours the terms conduct problems and behavioural problems will be used interchangeably in this essay.

Prognosis
There would appear to be a real need to 'nip problems in the bud' (Webster-Stratton & Taylor, 2001, p167) given the risks associated with early-onset conduct problems. 40% of 8 year old children with conduct disorder were repeatedly convicted in adolescence of offences involving vandalism, theft and assault, indeed 90% of juvenile offenders had conduct disorder in their childhood (Farrington, 1995; cited in Scott et al., 2001a). Children with conduct disorder have been found to be at increased risk of truancy, drug and alcohol abuse and of leaving school devoid of any qualifications (Farrington, 1995; cited in Scott et al., 2001b). In adulthood the picture remains bleak, with erratic employment in unskilled work, violent interpersonal relationships and continued offending occurring (Rutter, Giller & Hagell, 1998; cited in Scott et al., 2001a). By adolescence conduct disorder has been found to be
extremely resistant to treatment, therefore by intervening early the trajectories towards chronic antisocial behaviour may be altered (Fonagy et al., 2000). Herbert (1995) posits that without such an approach the long-term outlook for these individuals equates to a “revolving door of the social services, mental health agencies and criminal justice systems” (p.326). In economic terms the cost incurred by such agencies is substantial (Scott et al., 2001a). Given the extent and pervasiveness of conduct disorder, coupled with the cost to society in social and economic terms it seems vital that interventions are applied early on, to which attention shall now be turned.

Parent Training Programmes

One particular intervention used for children with behavioural problems is known as parent training programmes. This is a somewhat generic term encompassing an assortment of different programme based treatments, such as Parent-Child Interaction Therapy (Eyberg, Boggs & Algina, 1995; cited in Webster-Stratton & Taylor, 2001), as well as the aptly named Helping the Non-compliant Child (Forehand & McMahon, 1981; cited in Fonagy et al., 2001). These have all largely stemmed from the pioneering work of Patterson, Reid, Jones and Conger (1975; cited in Webster-Stratton & Taylor, 2001) and Hanf (1970; cited in Webster-Stratton & Taylor, 2001). These programmes share, as the generic parent training term would suggest, a focus on parenting behaviours, and are traditionally based upon a social learning theory framework, assuming a parenting skills deficit (Golding, 2000). By teaching parents new ways of interacting with their children, changes in the child as well as parent are thought to ensue, in the form of reduced aggression and non-compliance in the child, as well as reduced use of physical means of discipline and more appropriate parenting skills in the parent (Golding, 2000). This approach therefore positions parents as the most effective agents of change of their child’s behaviour (Connolly, Sharry & Fitzpatrick, 2001).

The rationale for using parents to alter their child’s behaviour has a strong empirical basis. Several behaviours in parents have been repeatedly shown to be associated with long-term conduct problems, namely inconsistent and harsh parenting, poor supervision, rejection of the child and little involvement in their activities (Farrington,
Patterson's (1982; cited in Webster-Stratton, 1997) work relating to the 'coercive process' was very influential in demonstrating how the negative patterns of interaction between parent and child can escalate and be maintained by the parents' responses.

As mentioned above several different programmes have been developed. It is not possible to discuss them all within the context of this essay, therefore studies arising from the Webster-Stratton programme will be focused on.

**Evidence base**

The original format, known as the BASIC programme, incorporated child directed play approaches from Hanf and Kling (1973; cited in Webster-Stratton, 1997) and Forehand and McMahon (1981; cited in Webster-Stratton, 1997), as well as Patterson's (1982; cited in Webster-Stratton, 1997) discipline components such as logical and natural consequences and time out (Webster-Stratton, 1997). It comprised approximately 13 weekly sessions of two hours in which 250 brief vignettes of parents and children interacting were shown and discussed within a group discussion videotape modelling format involving 2 therapists and 8-12 parents. Topics included how to play with young children, the use of praise and rewards, setting appropriate limits and non-violent discipline techniques such as time out. The use of videotape modelling was thought to be particularly advantageous in illustrating a variety of operant techniques for dealing with behavioural problems and providing a range of models in different settings encountering different situations (Webster-Stratton, 1984).

Webster-Stratton (1984) evaluated this type of format compared to individual therapy in a randomised trial for parents with conduct disordered children. She found that the group treatment was just as effective in reducing non-compliance within the child compared to individual therapy. These gains were maintained at one year follow up. From this study it would seem that both treatments offered equivalent benefits, however the group treatment was much more cost-effective with therapist time totalling 251 and 48 hours for the individual and group treatments respectively (Webster-Stratton, 1984). This programme fell under what became known as 'The
Incredible Years: parents and children series’ (Webster-Stratton & Taylor, 2001). The efficacy of this programme has been evaluated in a number of published randomised trials (Webster-Stratton & Taylor, 2001), with the superiority of this approach consistently being demonstrated, over others and wait-list controls, in reducing conduct problems. However Blackman (2002) notes that efficacy is somewhat different from effectiveness in evaluating research. The former involves examining whether or not the intervention under investigation can work in highly ideal and controlled experimental situations, whereas effectiveness is concerned with determining if an intervention actually works in everyday real life situations (Blackman, 2002).

Given the above distinction, and that this essay is concerned with discussing the evidence for effectiveness, studies conducted in real life settings will be focused upon. However these are somewhat thin on the ground (Webster-Stratton, 2001). In 1998 Taylor, Schmidt, Pepler and Hodgins conducted a randomised controlled trial in an applied setting. They compared a Webster-Stratton parent training programme, with an eclectic treatment typically offered, to a wait-list control group with parents of children between 3-8 years presenting with conduct problems, and found that both treatment groups were superior to the wait-list control, with particularly the parent training programme leading to the greatest reduction in child behaviour problems and greatest parent satisfaction with treatment. However this research was based in Canada, and as Fonagy et al. (2000) notes a significant amount of the evidence has come from research conducted outside of the United Kingdom (UK), particularly the United States (US). It is not known to what extent the results can be generalised to the UK (Fonagy et al., 2000). With this in mind the study conducted by Scott et al. (2001b) will be particularly focused upon. In one of the few controlled trials conducted in the UK for group-based parent training Scott et al. (2001b) allocated 141 parents of children aged 3-8 years referred with conduct problems to either a wait list control group or a parent training group which utilised the Webster-Stratton BASIC videotape discussion programme. Outcome measures in the form of a semi-structured parent interview, the child behaviour checklist and strengths and difficulties questionnaire, as well as direct observation of the parent-child interaction were employed. This study found that parents in the intervention group increased the
amount of child praise to ineffective commands threefold, whilst in the control group this was reduced by a third. Children of parents in the intervention group showed a large reduction in their behavioural problems, whereas no change occurred in the wait-list group.

Evaluation of the evidence base

Although parent training programmes have appeared to produce effective results in treating behavioural problems in children (Webster-Stratton, 1997) the evidence base warrants investigation.

The setting in which research has been conducted has a large impact on the effectiveness of the intervention. Scott et al. (2001b) note that many trials of parent training programmes have been conducted in artificial settings, such as university research clinics by extensively trained staff, and have used unrepresentative samples such as volunteers which may exclude many unmotivated and disadvantaged families. The effects of the setting in which research is conducted seems striking, for in a meta-analysis of published psychological treatment trials for childhood disorders the effect size found in university settings was substantial, from 0.71 to 0.84 SD, this contrasts with no significant effects found in a review of 6 outcome studies conducted in health clinics since 1950 (Weisz, Weiss & Donenberg, 1992; cited in Scott et al., 2001b). This poor outcome could be due to the complexity of cases seen in clinics coupled with increased demands on therapists (Scott et al., 2001b). Despite this there have been outcome studies conducted in clinical 'real life' settings (e.g. Connolly et al., 2001) which have found parent training programmes effective in reducing behavioural problems in children as measured by the Child Behaviour Checklist (CBCL; Achenbach & Edelbrock, 1991; cited in Connolly et al., 2001).

One element that has influenced the 'effectiveness' of these programmes has been the measures by which they have been evaluated. Connolly et al. (2001) only used a single measure relating to behavioural problems, the CBCL, in their study, and this was completed through parental report. This is somewhat limiting and multiple methods of assessment have been recommended (Chambless & Hollon, 1998; cited in
Nixon, 2002), particularly incorporating objective, that is independent evaluation, of the behaviour being examined (Nixon, 2002).

Some attention needs to be paid towards the size of the sample investigated, as much of the evidence for parent training programmes is based on studies which have used small samples, for example Taylor et al. (1998). This obviously has implications for the generalisability of the results. Furthermore in terms of co-morbidity some studies such as Scott et al. (2001b) have excluded children in their sample who had coexisting diagnoses such as encopresis and post-traumatic stress disorder. Within this study the rationale was that these conditions required additional treatment which would make it problematic to differentiate which intervention was having an effect. This appears to leave a gap in the evidence base, for in everyday clinical practice it is quite likely that children will present with behavioural problems as well as with coexisting disorders. This has yet to be addressed.

It is noted that methods of child control are highly culturally based, and therefore ethnicity and culture are important factors to be taken into consideration in training programmes (Fonagy et al., 2000). Scott et al’s (2001b) study does provide details of the number of parents in each condition who were from ethnic minority groups, however the range of ethnic groups included and the proportions of these are not known. Furthermore there seems to be little attention paid towards the reliability and validity of outcome measures used in these programmes with people from ethnic minority groups for whom such measures were not designed (Nixon, 2002).

A further feature of much of the evidence base is that the sample appears to be poorly defined (Nixon, 2002). This is not restricted to ethnicity as mentioned earlier, but also to the lack of details regarding the clinically defined disorder which children in the sample are presenting with (Nixon, 2002), for example in Sutton’s (1992) study no details are given as to whether the children met any of the diagnostic criteria for the various externalising disorders as defined in DSM IV (APA, 1994), and if so to what extent. In order to facilitate like with like comparisons, and give greater clarity as to what works for whom, the need for studies to be disorder specific has been emphasised (Kendall & Morris, 1991; cited in Nixon, 2002).
The effectiveness of these parent training programmes is evidenced by the outcomes they achieve, which are usually demonstrated by a reduction of behavioural problems seen in the child and an increase in effective parenting skills seen in the parents (Golding, 2000). The clinical significance of these results is important to establish, although within the literature there is no single or fixed meaning to denote clinically significant change (Kazdin, 1999; cited in Nixon, 2002). Therefore studies have used their own determinates of clinical significance, for example when using the Child Behaviour Checklist (CBCL; Achenbach & Edelbrock, 1983; cited in Webster-Stratton, Hollinsworth and Kolpacoff, 1989) Webster-Stratton et al. (1989) have used a score of 63 or lower, given that the CBCL authors specified this as the cut off between normal and clinical samples. Another way used to assess for clinical significance has been a 30-50% reduction of the behaviour examined, either through report or observation (Webster-Stratton et al., 1989), based on studies such as Patterson (1974; cited in Webster-Stratton, et al., 1989) who have identified this amount as an indicator of treatment success. Given that different studies are using different criteria to define success and significance, drawing comparisons and conclusions between them becomes more problematic.

Many studies relating to parent training programmes (e.g. Taylor et al., 1998; Scott et al., 2001b) have not included a follow up period to establish whether improvements in the child’s behaviour were maintained, or have typically confined this follow-up period to one year (e.g. Webster-Stratton et al., 1989). This seems to be an important area currently neglected, with little evidence existing for the long-term maintenance of treatment gains (Fonagy et al., 2000). This would appear to be of crucial importance in establishing the effectiveness of this early intervention. One long-term follow up study was that of Long, Forehand, Wierson, and Morgan (1993) who conducted a 14 year follow up of 26 adults whose mothers had participated in parent training when their child was between 2-7 years. Using a matched comparison group of adults whose mothers had not participated in parent training, Long et al. (1993) assessed multiple areas of functioning such as emotional adjustment and delinquency and found no differences to the comparison group which led them to attest to the long-term effectiveness of early parent training programmes. However the measures...
used were all self-report, and participants were paid for their inclusion in the study. A control group was also not a feature of this research (Long et al., 1993).

Indeed a common methodological problem is the lack of control groups in the evidence base (Golding, 2000). This is a limitation which is frequently referred to in the Webster-Stratton studies (e.g. Webster-Stratton, 1984). As it is unethical to withhold treatment for any significant amount of time the waiting list control group are incorporated into the intervention at a later point. This means that it is not possible to state what the effects might have been had the control group remained untreated (Blackman, 2002).

Generalisation to other settings is another important issue in evaluating the effectiveness of parent training programmes for reducing conduct problems in young children. Generally studies (e.g. Connolly et al., 2001) have not included measures of how children behaved in other settings such as school. Although in this study it may seem justifiable as no intervention occurred in this setting, it does not give an indication of whether generalisation occurred to other environments following treatment. This seems to be a common failing of much of the evidence base, with little evidence documenting generalisation from the home to settings such as school (Fonagy et al., 2000). Although approximately two thirds of children under 10 whose parents take part in these programmes show improvements in behaviour at home (Fonagy et al., 2000), 30%-50% continue to have significant problems at school in terms of conduct, peer rejection and academic underperformance (Webster-Stratton, 1997). This will be focused on further when discussing child training programmes.

Although Scott et al.'s (2001b) study generally found improvements within the intervention group compared to the wait-list control group, it is interesting that a third of the children still met the criteria for oppositional defiant disorder. This figure of approximately one third of children not improving following treatment has been typically cited in many other studies (Webster-Stratton & Hancock, 1998; cited in Golding, 2000). One reason for this is that factors known to be associated with poor outcome, such as socio-economic disadvantage, poverty, parental depression, and lack of family support have not been a focus for intervention (Webster-Stratton &
However in 1987 the ADVANCE programme was devised which sought to address other family risk factors for children's behavioural problems such as marital conflict, depression and lack of support (Webster-Stratton, 1997). Topics included problem solving, anger management, communication skills, how to give and receive support from others, as well as ways to manage upsetting thoughts and depression (Webster-Stratton & Taylor, 2001). This was designed to be appended to the BASIC programme, and therefore constituted an additional 10-14 weeks (Webster-Stratton & Taylor, 2001). Interestingly when evaluated in a randomised controlled trial no differences were found between parents in the 2 treatment groups, comprising the BASIC programme or that plus the ADVANCE programme, on the child behaviour variables. Both groups had made significant improvements, however parents in the ADVANCE group showed significant improvements in problem solving and communication skills compared to the other treatment group (Webster-Stratton, 1994; cited in Nixon, 2002). Thus it can be seen that parent training programmes have broadened their focus to include other risk factors thought to be involved in the development of child conduct problems. Greater emphasis has been given towards raising parental competencies, as opposed to just targeting and reducing conduct problems (Webster-Stratton & Taylor, 2001). However some parents may be unable or unwilling to participate in parent training programmes. In these instances child training programmes may be the only means available through which to work to reduce conduct problems (Webster-Stratton, 1997).

**Child Training Programmes**

Although many child training programmes have been devised since the 1980s typically these have not focused specifically upon children with conduct problems, neither have they been developmentally appropriate for very young children, being too cognitively sophisticated, nor have they incorporated direct behavioural observations of the child and parent at home, which is a very valid measure (Webster-Stratton, 1997).

Now broader focused training programmes have been devised which encompass interpersonal skills, communication and problem solving specifically for children
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(Golding, 2000). These are founded on the theory that children with conduct problems often show cognitive as well as behavioural deficits with their peers (Webster-Stratton, Reid & Hammond, 2001). Thus more of an ecological approach is being adopted with multiple risk factors being targeted in the development of child conduct problems (Golding, 2000).

Evidence base
The effectiveness of this broader approach can be demonstrated in a study conducted by Webster-Stratton et al. (2001) who randomly assigned 99 children with early-onset conduct problems between 4-8 years old to either a treatment or waiting list control group. The treatment employed the Incredible Years Dinosaur Social Skills and Problem Solving Curriculum. As the name suggests this was a child social skills and problem solving training programme specifically designed for 4-8 year olds with conduct problems. It incorporated videotape modelling methods, as well as role play, and fantasy play with puppets, and included empathy training, ways to build self-esteem, problem solving, anger management, academic, friendship and communication skills, and comprised approximately 20 weekly sessions with two therapists. This was a methodologically sophisticated study and used multiple measures, related to conduct and social problem solving, reported by multiple sources namely parents, teachers and independent observers. At post treatment the treatment group showed significantly less externalising behaviours at home and aggression at school, as well as more prosocial behaviour with peers and positive problem solving strategies. The researchers concluded that reductions in conduct problems were possible without direct parent intervention, however there remained one third of parents of the treated children who wanted more intervention following this programme (Webster-Stratton et al., 2001).

As with any of these programmes, by limiting the focus the effects are also likely to be limited (Webster-Stratton, 1997). The combination of parent training coupled with child training incorporating 'dinosaur school' produced the most effective results in a recent randomised controlled trial (Webster-Stratton & Hammond, 1997). Here 95% of families who received both parent training and child training continued to show significant improvements in the child’s behaviour when assessed at one year follow
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up. This was significantly higher than either parent training or child training alone (Webster-Stratton & Hammond, 1997). The lack of generalisation between the child’s behaviour in the clinic setting to school was a feature of this study. Peer groups and teachers were not directly involved, therefore the use of classroom based interventions which specifically incorporate these factors may offer great potential as a further means to reduce conduct problems (Webster-Stratton et al., 2001). Indeed many multi-focused interventions in which parent training is combined with other aspects such as classroom based programmes are currently being conducted, the most comprehensive of these being the US ‘Fast Track’ programme (Webster-Stratton & Taylor, 2001).

**Evaluation of the evidence base**

In evaluating the evidence base relating to child and also parent training programmes most of the outcome studies have combined preschool and primary aged children in their sample, indeed it is very rare for solely preschool children to be the focus of the programme investigated (Nixon, 2002). Given the developmental differences caution needs to be exercised when drawing conclusions about the treatments for preschool children based on children who are primary school age and above (Nixon, 2002). The claim that such programmes are more effective at younger ages has not been substantiated in the longitudinal research (Fonagy et al., 2000). However it would seem that the younger the child is when parents participate in treatment the larger the effects tend to be in terms of fewer dropouts, better gains and greater maintenance (Fonagy et al., 2000).

The duration of these programmes typically places a substantial demand on children’s and parents’ time, for example Webster-Stratton and Hammond (1997) required parents and children to attend a weekly 2 hour session for nearly 6 months. As the majority of children seen in clinic drop out of treatment after 10 sessions (Weisz, Thurber, Sweeney, Proffitt & LeGagnoux, 1997; cited in Nixon, 2002) it would seem that there is a need to shorten such programmes (Nixon, 2002). However the duration seems to contribute towards its effectiveness, for Kazdin (1997; cited in Golding, 2000) found that programmes of shorter duration, particularly those less than 10 hours, appeared to be less effective than programmes lasting 50-60 hours. It may be
that modified methods of delivery such as using the telephone, which Sutton (1992) examined, or internet may make such programmes more accessible and thus reduce attrition, although this has yet to be investigated (Nixon, 2002).

The author has found little evidence relating to the effectiveness on specifically child training programmes concerning conduct problems conducted in the UK. It would seem that evidence within this area is somewhat lacking.

Implications
In spite of all the problems mentioned with the evidence, parent training programmes have been found to be the single most effective intervention for reducing behavioural problems in young children (Brestan & Eyberg, 1998; cited in Webster-Stratton et al., 2001). Given the evidence base some form of parent training programme should be provided by all child mental health services for children under 8 (Fonagy et al., 2000). At this present time the Webster-Stratton videotape modelling group discussion programme has the strongest evidence, and is also the most cost-effective (Fonagy et al., 2000).

However in order to increase accessibility of such parent training programmes, and also reduce stigma they may be better placed in community settings rather than being delivered in traditional mental health services (Scott et al., 2001b). Training other professionals in child management techniques such as health visitors, who have a great deal of community involvement has been recommended (Fonagy et al., 2000). Indeed there are some moves towards this with the manualised parent adviser training (Davis & Spurr, 1998; cited in Fonagy et al., 2000). However as many of the factors associated with poor outcome e.g. marital conflict, depression and poverty, span across services “more intensive, multi-component, community based interventions involving more than one agency may be needed” (Fonagy et al., 2000, p.471). One example of this which has yet to be evaluated is the Sure Start programme (Glass, 1999). This is modelled on US programmes such as Head Start and the Perry Pre-School programme (Glass, 1999). The latter was a multi-component intervention combining family support with early child education in the first 5 years. Home visiting was employed, and compared to the control group many long-term gains were
made in terms of education and employment, as well as fewer arrests in adulthood. Interestingly although behaviour was not directly targeted it seems this intervention had an indirect effect on behaviour (Fonagy et al., 2000). Also no differences were apparent initially between the control and intervention group, these occurred in later follow ups (Little, 1999). Thus the effects of early intervention approaches may be delayed for many years, which needs to be taken into account in any evaluation (Little, 1999).

Conclusion
Given the prevalence and prognosis associated with conduct problems it would seem that there is a real need to nip such problems in the bud. It is not possible to make a blanket statement that 'early intervention works' given the heterogeneity of approaches involved, and therefore 2 particular approaches, that of parent training and child training programmes from a Webster-Stratton orientation have been focused on within this essay. The evidence for the effectiveness of these approaches has been discussed and it would seem that there are clear gaps in the evidence base, for example few methodologically strong UK studies have been conducted, and there is a dearth of longitudinal research. Furthermore there are clear methodological problems relating to the samples, measures, and design of the studies which comprise the evidence and make the assertions relating to effectiveness of these programmes. In spite of this the use of parent training programmes with younger children has been recommended as the intervention of choice for conduct problems in a recent review of the evidence base (Fonagy et al., 2000). Clearly 'early intervention works' for some children, but not all given that typically one third of the children are cited as not improving following these programmes (Scott, 1998). It is clearly not a panacea for all, and much more evidence arising from methodological strong research conducted in applied settings, possibly incorporating other factors known to be associated with poorer outcomes, is needed to bolster the effectiveness of these early intervention approaches.
References


Critically discuss the similarities and differences of the characteristics of suicide in older people and younger adults. Consider the implications for assessment and service delivery in clinical psychology.
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Introduction

Suicide is regarded as 'self-chosen behaviour that is intended to bring about ones own death' (Shneidman, 1985; cited in Leenaars, Wilde, Wenckstern, & Michael, 2001, p150). According to the National Suicide Prevention Strategy for England on average a person dies every 2 hours as a result of suicide (Department of Health, 2002). This equates to approximately 5000 people per year taking their own life (Department of Health, 2002). However such deaths have been predicted to increase as markedly more suicides have occurred within the large post war baby boom cohort than preceding generations (McIntosh, 1992; cited in Conwell, 2001). As these people enter later life the rates of suicide are expected to rise above that of the current older people cohort (Conwell, 2001). Indeed as older people comprise the fastest growing proportion of the population, the rate of older people suicides has been estimated as doubling by 2030 due to this demographic change alone (Haas & Hendin, 1983; cited in Conwell, 2001). Furthermore the impact of suicide on survivors is significant given the heightened risks of psychiatric morbidity and mortality from suicide (Ness & Pfeffer, 1990; cited in Conwell, 2001).

Given the real need to reduce the rate of suicides, it seems first necessary to explore the characteristics of those individuals who are most likely to engage in this act. This essay will particularly focus on completed suicides when discussing the characteristics of individuals who commit suicide. For the purposes of this essay older people will be regarded as individuals of retirement age, whereas younger adults constitute particularly young individuals of working age, unless otherwise stated. The similarities in the characteristics of suicide in older people and younger adults will first be discussed, followed by the differences. Consideration will then be given to the methods by which these findings arose. Finally the implications these characteristics hold for assessment and service delivery in clinical psychology will be discussed, with a focus being particularly placed upon older people.
Similarities

Gender

In terms of gender for both older people and younger adults being male appears to be a characteristic associated with suicide. Figures from the recent National Confidential Inquiry show that for younger adults males are certainly in the majority compared to females (Appleby et al., 2001). However for older people studies have shown more similarities in the gender split (e.g. Cattell 1988, & Cattell and Jolley, 1995). Although in a more recent UK study of 195 older people suicides, males outnumbered females by 2:1, with 67.7% of this descriptive case series being male (Harwood, Hawton, Hope & Jacoby, 2000). This difference has been attributed to changing rates in suicide between the genders, with a greater reduction in the numbers of older women committing suicide than older men in the last 15 years (Kelly & Bunting, 1998). Furthermore it would seem that there has been a dramatic increase in the rate of suicide in young adult males, though the overall rates of suicide remain highest in men in aged 75 years and over (Dennis & Lindesay 1995). It would seem then that for both younger adults and older people, being male is a risk factor for suicide.

Social isolation

Social isolation appears common to both older people and younger adult suicides. In Harwood et al’s., (2000) study of older people suicides about half of the sample were living alone. This contrasts markedly with the census data of that time which showed just over a quarter of people over 60 years living on their own, a finding which Cattell (1988) in his analysis of information from coroners’ inquests on 104 older people suicides also reported. Similarly when compared with the UK census data the proportion of suicides involving single, divorced or separated older men was markedly greater (Harwood et al., 2000). Furthermore in terms of being widowed there was a higher proportion of widowed women in the suicide sample than widowed men (54% to 28% respectively), which can perhaps be explained by the greater longevity typically experienced by women (Harwood et al., 2000). Indeed within epidemiological surveys a higher incidence of suicide in individuals who are currently not married seems to be a well established finding (Kelly & Bunting, 1998). Retirement and bereavements may also compound social isolation (Woods, 1996). For
younger adults suicides, unemployment and well as being unmarried and living alone are common features (Appleby et al., 2001).

**Dementia**

Dementia does not appear to be a characteristic of suicide in younger adults or older people. Harwood, Hawton, Hope and Jacoby (2001) found rates of dementia to be significantly higher in their control group than in the suicide group, suggesting that dementia did not feature greatly in older people suicides. However a limitation of this study was the high rates of dementia within the control group, which was not representative of the older people population as a whole. Thereby comparison was being made with a skewed sample, which clearly has implications for the validity of results. The risk associated with completed suicide in dementia is thought to be reduced given the changes in executive functioning and increased levels of supervision from carers as the disease progresses (Conwell, 2001). However in mild dementia where depressive symptoms often feature the risk is unclear (Conwell, 2001). Certainly very few cases were found in the recent National Confidential Inquiry, with the youngest adult being 52 years of age (Appleby et al., 2001). Consequently from the available evidence to-date dementia does not seem to feature heavily as a characteristic of either older people or younger adult suicides.

**Hopelessness**

Hopelessness has been consistently found to be related to suicidal ideation, intent and completed suicide in adults (Beck, Steer, Kovacs & Garrison, 1985, Fawcett et al., 1987; cited in Weishaar, 1996). This construct refers to a series of negative beliefs, in the absence of any positive beliefs about the present and future (Pearson & Brown, 2000). Hopelessness has also been focused on to a lesser extent in older people (Conwell, 2001), although more studies are now exploring this (e.g. Conaghan & Davidson, 2002). It would appear that hopelessness is an important characteristic of suicides in both groups, although for older people further research is required into the mediating role of other variables such as depression, and pain, and also the role of self-efficacy or locus of control, which may have specific implications for intervention (Conwell, 2001).
Method used
The most common means of suicide were found to be self-poisoning and hanging across all age groups (Appleby et al., 2001). In spite of this commonality there are important age differences, for example older people in the National Confidential Inquiry had the highest proportion of suicides by drowning, whilst jumping was proportionally higher in younger groups (Appleby et al., 2001). Gender differences are apparent, with hanging, carbon monoxide poisoning by car exhaust fumes and shooting being more common in older men than older women, whereas for older women prevalence is greatest for drug overdose (Harwood et al., 2000). However in line with previous UK studies shooting is rarely used in the UK, whilst in the USA it comprises the most common method (Harwood et al., 2000). Thus although it appears that there are similarities in the methods used by these two groups it is important to acknowledge that there are differences also. It is these differences in the characteristics of older people and younger adults suicides to which attention shall now be turned.

Differences
Psychiatric conditions and physical health
There are considerable differences in the psychiatric disorders which older people and younger adult who commit suicide have been diagnosed with. In terms of personality disorder Harwood et al. (2001) found this to be present in 16% of older people who committed suicide. This figure is considerably lower than the 30-40% found in young adults in a study conducted by Appleby, Cooper, Amos and Faragher (1999). Similarly rates were markedly different between younger adults and older people who had schizophrenia and other delusional disorders in the recent National Confidential Inquiry report (Appleby et al., 2001). This evidence would suggest that personality disorder is more characteristic of suicides in younger adults than older people.

A history of drug or alcohol abuse, or a diagnosis of alcohol and/or drug dependence was higher in younger adults than older people in the National Confidential Inquiry (Appleby et al., 2001). For older people Cattell’s (1988) study showed 29% to have alcohol in their blood at post mortem, which corresponds roughly to 22% found in a
Affective disorders such as depression appear to be common in both younger adult and older people suicides (Appleby et al., 2001). However typically the type of depression found in older people is not co-morbid with psychoses or other psychiatric illness such as substance disorder unlike that found in younger adults (Pearson & Brown, 2000). In older people it is often the first episode, and mild to moderate in severity (Cattell, 1988). Studies of suicide in older people have regularly found that more than half of the individuals had a depressive disorder at the time when they committed suicide (e.g. Barraclough, 1971). These findings are similar to those of Harwood et al.'s., (2001) recent study which sought to explore the rates of psychiatric disorder in older people who committed suicide. They found that nearly two-thirds, that is 63%, had depression at the time of death, and depression emerged as the only psychiatric disorder which acted as a predictor of suicide in the case-control analysis (Harwood et al., 2001).

Acute and chronic physical health conditions are particularly prevalent in older people (Conwell, 2001). Indeed deterioration in physical health at the last time of contact was found in 23% of suicides occurring in individuals over 65 years in the recent National Confidential Inquiry (Appleby et al., 2001). This deterioration in physical health was associated with older age, possibly arising from a stroke or fall, which suggests it does not feature greatly in younger adult suicides. Furthermore this deterioration was noted at the time of last contact, however the National Confidential Inquiry sample is restricted to individuals who had been in contact with mental health services in the year before they committed suicide (Appleby et al., 2001). In one recent study only a quarter of older people who had committed suicide had been in contact with psychiatric services in the year before their death (Harwood et al., 2000). Such rates are typically higher for younger adults (Pirkis & Burgess, 1998). Thus details relating to the majority of older people suicides will not be listed in the National Confidential Inquiry, as they generally will not have accessed these specialist services, utilising instead primary care (Pearson & Brown, 2000). Cattell and Jolley (1995) found 43% of older people who had committed suicide had seen
their GP within a month of doing so. This figure is similar to that of Harwood et al., (2000) whereby half their sample had been in contact with their GP in the month prior to suicide. A quarter of individuals had seen their GP a week before, and for 7.2% within 24 hours of their death. However over half of the consultations were primary for physical complaints (Harwood et al., 2000). The tendency towards somatization in older people has distinct implications in assessing the risk of suicide which will be discussed later.

**Previous attempts**

Younger adults attempt suicide more, but older people are more successful at completing it (Conwell, 2001). This has been attributed to younger people being typically more impulsive, with older people being more intent in their efforts to commit suicide and so engage in greater planning (Conwell, 2001). However such intent may not be kept hidden, for Harwood et al. (2000) found that nearly half of their sample of 195 older people suicides had communicated this intent at some point in the year previous to them committing suicide. This intent to commit suicide will have implications for assessment and intervention as will be discussed later. In terms of previous attempts Hawton, Houston, and Sheppard (1999) found that 44.8% of young people under 25 years who had committed suicide had a history of making a previous attempt. This figure is slightly greater than that found in a study exploring previous attempts in older people, where the rate was 37.9% (Harwood et al., 2000). Linked with previous attempts are acts of deliberate self-harm which have been found to occur more in younger adults (Appleby et al., 2001), although do appear to constitute a serious indicator of suicide risk if conducted in individuals who are advancing in years (Hawton, Zahl & Weatherall, 2003).

**Methodological factors**

Conwell (2001) notes that it is a constellation of these characteristics rather than any one single factor which heightens the risk of an individual committing suicide, with such a constellation likely to differ between individuals. Furthermore these are just characteristics and do not provide causal information as to why somebody chose to take their own life. This information is difficult to acquire from the studies conducted to-date given the topic area and the methodology used. Such difficulties
can be explored by examining Harwood et al's. (2001) study which furthered the work of Cattell (1988) and Cattell and Jolley (1995), and claimed to be the largest psychological autopsy of suicide in older people conducted. Here details were collected on a consecutive series of older people aged 60 years and above who had died between 1995 and 1998 and lived in a wide geographic area. Multiple sources of information were used including psychiatric records, coroners’ inquest notes, GP case notes and informant interviews. Verdicts of open or accidental death which seemed to indicate probable suicide were also included. Despite the rigorousness involved, the initial sample of 195 was substantially reduced particularly due to informants declining to participate. Furthermore there were difficulties finding appropriate matched controls, and therefore the case-control study was reduced to a sample of 54. Thus given the small sample size the study lacked the statistical power to find more significant results (Harwood et al., 2001). Indeed small sample sizes are a common feature in much of the research in this area, due also to the rarity of the act (Pearson & Brown, 2000). Furthermore using third party information in psychological autopsies is known to be subject to certain biases, and limitations (Pearson & Brown, 2000). In an attempt to overcome this other methods such as suicide notes have been explored (Leenaars et al., 2001). However these also have limitations such as the intentional distorting of information in order to induce a particular reaction (Leenaars et al., 2001).

Generally research has excluded participants who have suicidal ideation, given the ethical and medico-legal implications (Conwell, 2001), however to increase the knowledge base in this area it would seem that studies which compare completed suicides against adequate control groups are warranted as are prospective studies which further explore the risk factors for suicides in older people (Pearson & Brown, 2000). Furthermore given the high rates of certain characteristics associated with suicide within older people such as depression, physical illness and social isolation the positive predictive power of these variables for suicide seems rather low, and thus research into variables such as hopelessness, intent, as well as social support is needed (Dennis & Lindesay, 1995). Thus currently there seems to be a rather incomplete evidence base, however in the meantime individuals who are at risk of suicide still need to be discovered, and assessed.
Older People Essay

Assessment
From the evidence available it would seem that the characteristics of suicide in older people and younger adults are generally quite distinct, although there are some similarities in terms of being male and socially isolated. However within older people suicides, depression and physical illness appear to be prominent features, whereas within younger adults schizophrenia, personality disorder and substance misuse appear to be more typical characteristics. It seems important that these factors are taken into consideration at assessment. However for older people in particular it would seem that recognising them as at risk is particularly problematic for a number of reasons.

Older people may not initially present themselves to services, often being more resistant than younger adults in admitting they need help (Lesnoff-Caravaglia, 1987; cited in Miller, Segal, & Coolidge, 2001). This could be viewed as a particular cohort effect, with these older people having lived through World War II, which may well have promoted different attitudes towards hardship, and dealing with difficulties (Woods, 1996). Other factors such as living in remote areas or being housebound through physical illness (Conwell, 2001) may further impact upon them presenting to services.

Furthermore if they do seek help as mentioned this is likely to be from their GP, and thus unlike younger adults who are suicidal may rarely come into contact with psychologists (Pearson & Brown, 2000). A variety of factors are likely to impede the detection of these individuals being at risk of suicide. Older people are more likely to report their affective symptoms in somatic terms (Heithoff, 1995; cited in Conwell, 2001), they are less likely to voluntarily give information relating to their affective state (Lyness et al., 1995; cited in Conwell, 2001), and they may view their feelings as normal and as an inevitable effect of ageing (Conwell, 2001). One of the key elements of preventing suicide in older people listed in the National Service Framework for older people is the early recognition and treatment of depression within primary care services (Department of Health, 2001). However for the reasons mentioned above this may prove difficult to do. Furthermore physicians typically lack the time, knowledge and skills in which to assess for depression and suicide risk,
and may also hold biased attitudes about ageing and mental health (Conwell, 2001). There are clear implications here for intervention which shall be discussed later.

Measures are available which could be used to aid the assessment process, such as the Beck Hopelessness Scale (Beck, Weissman, Lester & Trexler, 1974; cited in Weishaar, 1996) which in adults, when compared to other measures such as the Beck Self-Concept Test (Beck, Steer, Epstein & Brown, 1990; cited in Weishaar, 1996), has clinically been shown to be the most sensitive indicator of suicide risk (Weishaar, 1996). Specifically for older people the Geriatric Depression Scale (Yesavage et al., 1983; cited in Conwell, 2001) has been validated for use within primary care settings (Lyness et al., 1997; cited in Conwell, 2001). However these self-report measures are reliant on older people admitting their true feelings, which they may not choose to do. The findings of Miller et al., (2001) are particularly relevant here. They found no differences in the suicide ideation of younger adults and older people, which was surprising given the higher completed suicide rate amongst older people. They therefore concluded that older people were less inclined to reveal their intentions but more inclined than younger adults to commit suicide when such thoughts arise, which consequently makes assessment difficult. Miller et al., (2001) however also looked at reasons for living and found that moral objections, which incorporated religious beliefs, and child-related concerns were stronger reasons in older people than in younger adults for not committing suicide. Thus within an assessment it may also be clinically useful to identify protective factors such as reasons and beliefs which might deter an older person from committing suicide (Miller et al., 2001). Furthermore it would also ideally incorporate a detailed history including information relating to previous suicide attempts and intent (Harwood et al., 2000), identification of suicidal thoughts, plans and changes in behaviour and personality (Dennis & Lindesay, 1995), from the individual themselves and an informant should one be available (Harwood et al., 2001). However assessment on its own is unlikely to lead to a reduction in the rates of suicide, as appropriate intervention is needed. Such issues will be explored below.
Service Delivery
As discussed there are several differences in the characteristics of suicide within older people and younger adults. This has several implications for the delivery of services which shall now be discussed, with particular emphasis upon how this affects older people.

The government have recently set a target of reducing the number of suicides by at least one fifth by 2010 (Department of Health, 2002). Within the suicide prevention strategy certain groups of individuals such as young men have been particularly identified as being at high risk of suicide (Department of Health, 2002), whilst older people as a group have not been acknowledged as being at high risk of suicide, which further serves to keep the problem hidden, and awareness low. Similarly the recommendations made in 12 points to a safer service as identified in the National Confidential Inquiry (Appleby et al., 2001), which are to be implemented by local mental health services to improve clinical risk management (Department of Health, 2002), also appear geared to certain groupings, typically younger adults, who are or have been in-patients with a history of self-harm or violence, and are suffering from a severe mental illness co-morbid with substance abuse. As Harwood et al., (2000) found in their study only 3% of older people who committed suicide were in-patients at the time of death, and just 15.4% were under active out-patient or community team follow up. Therefore such recommendations in terms of changes in practice may not significantly reduce older people suicide rates given that the majority of older people at risk of suicide are rarely utilising mental health services anyway.

It would seem then that primary care is more important for older people than for younger adults who are at risk of suicide. The need for education and training within primary care, particularly in the area of screening for depression, and assessing suicide risk has been recognised (Department of Health, 2001). However given the difficulties around detection and attitudes as discussed earlier this is no easy task. Educating GPs about changing their practices also seems warranted, for a reduction in the availability of certain medication in older people who are at risk of suicide may be a useful preventative strategy (Harwood et al, 2000). Harwood et al. (2000) note that older people appear to be more susceptible to cardiotoxic effects of certain tricyclic
anti-depressants such as dothiepin, whilst certain analgesics such as co-proxamol if used in overdose are potentially lethal due to the respiratory depressant effect of the opiate component. It would seem that improving the prescribing of certain anti-depressants and analgesia in older people who are depressed may be a useful strategy in further reducing the rates of suicide in older people (Harwood et al., 2000). This measure seems akin to more systemic strategies in reducing the accessibility of specific means of suicide, which has been shown to be effective in the past, for example the detoxification of coal gas in the 1960s lead to a substantial reduction in the rate of older people suicides (Dennis & Lindesay, 1995). This also occurred following the standard fitting of catalytic converters (Dennis & Lindesay, 1995).

However reducing the availability of certain methods of suicide may not deter an individual who is intent on committing suicide, which clearly necessitates other strategies. Similarly as the causes of suicide are thought to be many it is therefore necessary to have multiple interventions (Conwell, 2001).

One of these would appear to be the prescription of information. Education amongst older people in dispelling myths around depression and suicidal ideation being a natural consequence of ageing is essential, coupled with information relating to signs of depression, and the benefits that treatment can provide (Conwell, 2001). Greater information to carers has also been acknowledged as being necessary (Department of Health, 2001). Greater awareness in younger adults is similarly needed (Department of Health, 2002). Thus in terms of psychologists delivering a service to older people and younger adults at risk of suicide it appears that working systemically is necessitated, not just in terms of working with the individuals, their carers, or friends but with other agencies as well, for it has been recognised that suicide cannot be dealt with by mental health teams alone and that collaboration with other services is needed (Department of Health, 2002). Such services would typically be different for older people than younger adults, e.g. voluntary agencies such as Age Concern. Health professionals such as psychologists have a valuable role in educating these services who may be the first source of contact with an older person who is at risk of suicide (Dennis & Lindesay, 1995). Thus greater integration amongst different services has been regarded as crucial in order to encourage early referral of individuals at risk and thereby heighten support and supervision (Dennis & Lindesay, 1995).
A further approach regarded as useful for older people in the community who may be depressed and at risk of suicide is the care programme approach (Dennis & Lindesay, 1995). This has been designed with the aim of providing co-ordinated care planning, and involves a nominated key worker keeping in regular contact with the older person, monitoring their needs and changes in circumstances (Dennis & Lindesay, 1995). This shares similarities with certain community outreach initiatives which have been shown to be valuable (Conwell, 2001), for example one approach involved older people at risk of suicide being provided with a portable alarm system, and having regular supportive telephone contact with a trained health professional, which produced only one death in four years, a significantly lower than expected rate (DeLeo, Carollo, & Dellobuono, 1995; cited in Conwell, 2001). The use of the care programme approach (CPA) comprises an important aspect of care management for individuals at risk of suicide (Department of Health, 1999). However given some difficulties with its utility recommendations have recently been made for a major overhaul of CPA with national criteria established for enhanced CPA, and care plans being made more explicit in terms of dealing with non-compliance and missed contact (Appleby et al., 2001). As well as care within the community for both younger adults and older people it would seem that in-patient provision is important (Appleby et al., 2001), with appropriate day care for older people in particular seen as invaluable (Dennis & Lindesay, 1995).

In terms of the evidence base relating to interventions for people who are at risk of suicide, few studies have explored the effectiveness of interventions in suicidal adults in general, and hardly any have done so within the older people population (Pearson & Brown, 2000). The use of cognitive therapy for older people who are feeling suicidal has been used successfully (Beck & Weishaar, 1990; cited in Pearson & Brown, 2000), however the efficacy of this intervention has rarely been explored in controlled treatment outcome studies, given the associated ethical implications (Pearson & Brown, 2000). In contrast much has been written regarding the efficacy of cognitive therapy in treating depression in adults (Gallagher-Thompson & Thompson, 1996; cited in Pearson & Brown, 2000) with depression being linked to suicidal behaviour via hopelessness as the mediating variable (Dyer & Kreitman, 1984 cited in Conaghan & Davidson, 2002). Thus as there are no proven
interventions that demonstrate reduced suicidal behaviour in older people the
detection and treatment of depression has been considered to be crucial (Pearson &
Brown, 2000). Certainly within the National Service Framework for Older People
cognitive behaviour therapy and other non pharmacological treatments for depression
have been recommended as the first line of management wherever possible, taking
place within a specialist mental health service, particularly if there is risk of suicide
(Department of Health, 2001). Certain adaptations to this are likely given features
such as sensory impairments and memory difficulties being more common in older
people (Woods, 1996). However as discussed earlier, the stigma of accessing such
services for older people who are less psychologically minded, and in possession of
certain values and attitudes regarding mental health, as well as physical illness and
social isolation may mean that the problem is not detected early enough or indeed at
all.

Conclusion
Although there is considerably more research needed in this area it would seem from
the information available to-date that the suicide characteristics of older people and
younger adults are somewhat different. By the very nature of these characteristics
older people at risk of suicide are more hidden than younger adults within society, and
consequently appear to be less visible in strategies designed to prevent suicide (e.g.
Department of Health, 2002). The assessment of suicide risk, as well the detection of
depression is particularly difficult within older people given some of the
characteristics mentioned above. It would seem that there is a real need to raise
awareness and work systemically with individuals, their networks and other agencies,
in order to prevent suicides from occurring in younger adults as well as older people.
References


CLINICAL DOSSIER

Overview
This section contains an overview of the clinical experience gained during the six clinical placements of the course, and brief summaries of the five clinical case reports submitted. The complete case reports, and full details of the clinical experience, including placement contracts, logbooks of clinical experience and placement evaluation forms can be found in Volume II of the portfolio. This is held in the Psychology Department of the University of Surrey due to the confidential nature of the information it contains. To preserve anonymity and confidentiality, clients' names have been changed and all potentially identifying details have been omitted.
Adult Mental Health Placement Summary

Placement details
Supervisors: Maeve Crowley, Consultant Clinical Psychologist; Fiona Spencer, Counselling Psychologist
Base: Horsham Hospital, Horsham, Sussex.

Summary of experience

Overview
This placement provided me with an initial introduction of using cognitive-behavioural therapy as well as concepts from the psychodynamic literature in working with adults who present with a range of mental health problems. During this placement I also devised and conducted a service related research project entitled 'Retrospective analysis of women assessed for a survivors of sexual abuse group: who attends and who drops out?'.

Models
This placement provided me with an initial introduction to working from a cognitive-behavioural perspective in the psychological treatment of adult mental health problems, as well as an insight into the application of some psychodynamic ideas. In addition the utilisation of a humanistic person-centred approach, namely the use of empathy and acceptance, aided my ability to form a healthy therapeutic relationship when working with clients.

Settings
The placement was based within a Psychology Department providing primary care services within a Community Hospital. Clinical work was undertaken in a psychology department and was out-patient based.
Clinical skills and experience

Clinical experience involved working with males and females (age range 18-66) from a predominantly white, British ethnic background, who presented with a range of problems including: anxiety (e.g. generalised anxiety disorder, social phobia and panic attacks), depression, eating disorder i.e. bulimia nervosa, loss/bereavement, alcohol abuse and post traumatic stress disorder. Experience was gained using a range of assessment measures (e.g. WAIS-III, NART, BAI, BDI-II, MOC and CORE).

Meetings, observations and seminars

During my placement I attended several psychodynamic group supervision sessions consisting of both clinical and counselling psychologists. I also attended many psychology department meetings. I observed my supervisor providing consultation and supervision to health professionals involved in running a female survivors of sexual abuse therapy group. In addition, to gain an insight into the work of a CMHT, I attended a CMHT meeting, and met with a Community Psychiatric Nurse and Occupational Therapist to discuss their role.
Adult Mental Health Case Report Summary

The Assessment and Treatment of a 32-year-old woman presenting with Panic Disorder and Agoraphobia using a Cognitive-Behavioural model.

Presenting Problem
Jane, a thirty-two year old Caucasian woman, was referred by her General Practitioner. She presented with complaints relating to panic attacks and claustrophobia of over 10 years. She reported being fearful of entering certain situations such as crowded environments or enclosed spaces for fear that she would have a panic attack. This was impacting upon her ability to lead a normal life.

Assessment
Jane was assessed via clinical interview and the administration of standardised measures. These included the Beck Anxiety Inventory (BAI; Beck, Epstein, Brown & Steer, 1988), and the Beck Depression Inventory-Second Edition (BDI-II; Beck, Steer & Brown, 1996). The Clinical Outcomes in Routine Evaluation form (CORE; Core System Group, 1998) was also administered routinely in line with departmental policy. Assessment revealed that Jane had 'severe' levels of anxiety and 'moderate' levels of depression.

Formulation
Jane's symptoms appeared to be consistent with a diagnosis of panic disorder with agoraphobia as defined by the Diagnostic and Statistical Manual of Mental Disorders (DSM IV; American Psychiatric Association (APA), 1994). The case was formulated by drawing upon Clark's (1986, 1988) cognitive model of panic.

It was hypothesised that Jane's early experiences of growing up with an anxious father predisposed her to view her environment as dangerous and unsafe. For Jane, getting stuck in a lift in early adulthood, may have acted as the initial critical incident, which precipitated panic-like symptoms. Now particular internal (e.g. thoughts) and external (e.g. environment) stimuli were selectively attended to and interpreted as signs of impending danger (e.g. 'I'm going to get stuck/trapped'). This produced
anxiety and accompanying physical and cognitive symptoms (e.g. difficulty breathing, heart racing, dizziness, dry throat) which Jane interpreted in a catastrophic way, that is, as indicative of imminent suffocation. This catastrophic misinterpretation heightened Jane’s anxiety, exacerbated her symptoms and allowed the vicious circle of panic to continue. However Jane escaped the situation or avoided it altogether therefore preventing disconfirmation of the feared catastrophe. She also engaged in various safety-behaviours (e.g. ensured windows were always in view, always carried a bottle of water) which further prevented disconfirmation of her fears. This would have led her to falsely attribute the non-occurrence of the feared catastrophe to the safety-behaviours themselves, which further served to maintain their use.

**Intervention**

As there is considerable evidence in the form of randomised controlled trials that demonstrate the effectiveness of cognitive therapy for panic disorder (e.g. Arntz & van den Hout, 1996) as well as studies showing that cognitive therapy is effective for panic disorder with a moderate degree of agoraphobic avoidance (e.g. Clark et al., 1994), a cognitive-behavioural approach to treatment was adopted. The planned intervention was based on a structure advocated by Wells (1997) for the treatment of panic disorder, as well as Butler's (1989) work on phobic disorders, which emphasised the use of exposure.

Jane was offered 6 sessions initially as is standard departmental policy, with 4 further sessions being given following a review. Initially socialisation to the cognitive-behavioural model occurred. Psycho-education on anxiety and panic attacks took place, and bibliotherapy used. The cognitive model of panic was presented and a recent episode used to track the course of Jane’s panic and highlight the link between thoughts, affect, behaviours and physiological symptoms. Jane found this conceptualisation helpful and reported it to be 'exactly like me'. Behavioural experiments were used to demonstrate the effect of thoughts on anxiety and accompanying physical symptoms, and a graded hierarchy constructed in order to guide work on exposure. This involved using relaxation exercises particularly imaginal exposure to facilitate real life exposure, as well as the removal of safety behaviours. The use of a panic diary was introduced in the session and set
collaboratively as a regular homework task. Negative automatic thoughts relating to Jane's catastrophic misinterpretations were identified, evaluated, and attempts at modifying these occurred using Socratic questioning. Various 'thinking errors' (Beck, 1976) were identified (e.g. arbitrary inference, emotional reasoning, selective abstraction) and focused on, and Beck's (1995) cognitive role play employed. At the end of the intervention progress was reviewed and relapse prevention issues discussed.

Outcome
During the course of the treatment Jane made progress up the graded hierarchy, and was able to enter several situations (e.g. shopping in a crowded supermarket, eating in a busy restaurant) which she had not done in many years. These gains also impacted upon other areas of her life, and she felt extremely pleased about these changes. However post-treatment scores did not alter significantly. Other information emerged during the course of the intervention, which may have accounted for this. As well as some obsessional-compulsive elements being present it seemed that Jane's overriding problems related to chronic and repeated worrying on a variety of issues, and that her difficulties might be more appropriately re-formulated in terms of generalised anxiety disorder (GAD), co-existing with panic disorder and agoraphobia. A re-formulation is given using Well's (1995) GAD model, and other considerations relating to the therapy discussed.

(A comprehensive reference list can be found in the appropriate case report in Volume II)
People with Learning Disabilities Placement Summary

Placement details
Supervisors: Dr Tessa Lippold, Consultant Clinical Psychologist
NHS Trust: Surrey Hampshire Borders NHS Trust.
Base: Greenlaws, Community Learning Disability Team Base, Guildford, Surrey.

Summary of experience

Overview
This placement provided an opportunity to develop my skills in behavioural and cognitive behavioural assessment, formulation and intervention. Working from within a multi-disciplinary team allowed me to develop my skills relating to team and organisational functioning. Furthermore I developed an appreciation of the need to work systemically with relatives, carers and other agencies in order to successfully meet the needs of this client group.

Models
This placement provided the opportunity to use both behavioural as well as cognitive behavioural assessment and intervention. Working with complex systems provided me with an introduction to thinking systemically about clients, and the systems of which they are a part.

Settings
This placement was based within a multi-disciplinary community learning disability team (CLDT). Clinical work was undertaken in a range of settings including: group homes, client homes, day centres and the CLDT base.

Clinical skills and experience
This placement developed my skills on a number of levels (e.g. direct clinical work with individuals and groups, indirect work with relatives and paid carers, joint work with other professionals and staff training). Clinical work was undertaken with males.
People with Learning Disabilities Placement Summary

and females (age range 17-63) from a predominantly white, British ethnic background with significant and severe learning disabilities, with various presenting problems including: depression, anxiety, autism, self-injurious behaviour, dementia, psychosis and anger management difficulties. A range of assessment procedures were used (e.g. WAIS-III, WORD, BPVS-II, Schonell Graded Naming Test, WASI, CARS, HALO, ABC charts, functional analysis questionnaire, direct observations, mood diary and emotions cards). Staff training to carers from 2 group homes on the issue of 'dementia in people with Down’s syndrome' was devised, conducted and evaluated. Furthermore I co-facilitated a group session on anxiety management as part of a multi-agency health promotion day (Feelgood 2002) for people with a learning disability.

Meetings, observations and seminars
I met with several members of the CLDT including the CN, SALT, OT, Music Therapist, Aromatherapist, and Team Co-ordinators to discuss their role. In addition I met with individuals from other agencies including day centre managers, a respite care manager and a co-ordinator of EmployAbility, a scheme which helps people with a learning disability find part-time employment. I attended several CLDT and psychology meetings which included presentations on topics such as Organisational Neurosis and feedback from Padesky's possibilities and hope seminar. In addition to presenting a case within group supervision, I jointly presented details regarding the psychological input which occurred at 'Feelgood 2002' to psychologists within the CLDT.
People with Learning Disabilities Case Report Summary


Presenting Problem
Donald, a sixty-three year old Caucasian man was referred by his day centre keyworker. The referrer registered concerns at the emergence of aggressive, self-harming behaviours, and specified the referral as urgent.

Assessment
As the referral had occurred via a third party, information about the assessment was provided and Donald’s consent obtained. Initial assessment occurred with Donald and his day centre keyworker in the form of a clinical interview. Donald was able to provide minimal information, which was supplemented by his keyworker, who also spoke about Donald having 'slowed down' recently.

Several hypotheses were generated with regard to Donald’s behaviour. These included the possible onset of a progressively degenerating condition such as dementia, as behavioural and emotional changes are often the first signs to appear in a dementing illness (Lai & Williams, 1989). A hypothesis of depression was also considered, particularly as these symptoms may be expressed more behaviourally in individuals with a learning disability (Aylward, Burt, Thorpe, Lai & Dalton, 1997). However as other causes for Donald’s changes in behaviour needed to be excluded first before dementia was considered (Aylward et al., 1997) an extended assessment was conducted.

In addition to speaking further with Donald and his keyworker, information was obtained from Donald’s group home support worker, Community Learning Disability Nurse, GP, Sister, and case notes. Indeed many systems were encountered in conducting the assessment, and detailed background information relating to Donald’s adaptive, communication, and cognitive skills, family history, social relationships, life events and losses, routines and preferences, living situation, history of professional
input and physical and mental health as well as medication were obtained. Several assessment measures were also used including the British Picture Vocabulary Scale-Second Edition (BPVS-II; Dunn, Dunn, Whetton & Burley, 1997), a functional analysis questionnaire (Willis & LaVigna, 1989), a shortened version of Hampshire Assessment for Living with Others (HALO; Shackleton Bailey & Hampshire Social Services, 1980), emotions cards, and an antecedent, behaviour, consequences chart (ABC chart).

**Formulation**
Several vulnerability factors, such as Donald's severe impairment of intellectual functioning, expressive and receptive communication difficulties, and institutionalisation as an adult, may have predisposed him towards engaging in the problem behaviour of self-injury, in that he would repeatedly hit his cheeks, chin and chest with his fists. Other agitated behaviours also occurred such as rapid repetitive speech, pacing and 'face pulling'. It was also noted that the self-injurious and agitated behaviour tended to occur following aversive events such as when Donald had lost his watch, and also after having his money stolen; during unstructured time, so that he was not engaged in sufficiently stimulating activities to distract himself from his concerns and/or possible feelings of boredom, and as a result of physiological changes which may have been occurring internally. In terms of protective factors Donald had good independence skills, which he valued as well as many interests such as trains and cats. The problem behaviour was hypothesised to be maintained through socially mediated positive reinforcement, that is, an increase in staff time and attention, through positive automatic reinforcement, namely the release of endorphins, and also through negative automatic reinforcement, that is the problem behaviours may have been used as a form of de-arousal.

**Intervention**
A constructional approach was taken to intervention, whereby other behaviours which served the same function and were more socially appropriate were substituted for the problem behaviour rather than being eliminated (Emerson & Kiernan, 1997). For the contingency of negative automatic reinforcement Behavioural Relaxation Training (Lindsay & Baty, 1986) was used directly with Donald on several occasions, and
guidelines given to staff at the day centre and his group home to facilitate utilisation of this technique in these settings. Staff also had a key role in altering the other types of reinforcement which was thought to be maintaining his behaviour; namely socially mediated positive reinforcement, and positive automatic reinforcement. In addition as it was considered that staff tended to overestimate Donald’s cognitive abilities given his adaptive level of functioning, education occurred with staff regarding more optimal ways of communicating with Donald. Thus there was a significant need to work with the systems that surrounded Donald.

Outcome
Following the intervention Donald appeared less agitated. Donald’s keyworker and sister reported that he had improved greatly. No further incidents of self-injurious or agitated behaviour were reported. Donald’s care manager also agreed to conduct a full reassessment of his needs, which it was hoped would lead to the provision of additional support for Donald in the group home environment. Information emerged towards the end of the intervention regarding Donald’s physical health which is discussed in light of the original formulation. Problems encountered as well as a critique of the work undertaken are also considered.

(A comprehensive reference list can be found in the appropriate case report in Volume II)
Children, Adolescents & Families Placement Summary

Placement details
Supervisors: Dr Martin Carey, Clinical Psychologist; Dr Natasha Gray, Clinical Psychologist.
NHS Trust: South London and Maudsley NHS Trust.

Summary of experience

Overview
This placement provided an opportunity to employ skills in the application of systemic therapy, and attachment theory to the clinical practice of working with children and families. In this work I was also informed by behavioural and cognitive-behavioural models. I was able to develop my experience of group work through co-facilitating a parenting course for parents of adolescents. The challenges of working with some very young children as part of ‘Sure Start’, adolescents and parents on this placement served to expand my repertoire of clinical skills. Furthermore the experience of working with individuals from different cultural and social backgrounds raised my awareness of the need to consider these factors in order to work effectively.

Models
This placement provided an opportunity to develop my theoretical understanding of different systemic models including Milan, post-Milan models such as Narrative therapy as well as Solution Focused Therapy and the application of these to working with children and families. Theories regarding attachment stemming from psychodynamic literature were also used. Furthermore there was some application of Behavioural and Cognitive-Behavioural theory.

Settings
This placement was based within a Tier 2, community child and family service. Clinical work was undertaken in a range of settings including: outpatient clinics at a GP surgery, client homes and schools within the borough.
Clinical skills and experience
Clinical experience involved working with children and adolescents (age range 1-14) from a range of ethnic backgrounds, as well as working with parents on a range of presenting problems including: school refusal, autism, temper tantrums, sibling rivalry, separation anxiety, attachment difficulties, social anxiety, sleep problems, attention deficit hyperactivity disorder, child sexual abuse, oppositional and conduct problems. Working with very young children as part of the Sure Start programme heightened my appreciation of the benefits of early intervention. In addition I was involved in a Parenting Teenagers Course for parents who were having difficulties with their teenage children. A range of assessment tools were used on this placement including the Strengths and Difficulties Questionnaire, Connors, WISC-III, WORD, Family Relations Test, Birleson Depression Inventory, Spence Children’s Anxiety Scale, and the 'All about Me' game.

Meetings, observations and seminars
In order to gain a greater appreciation of the other ‘systems’ which linked into the placement I met with several individuals including: an Educational Psychologist, Health Visitor, Sure Start Co-ordinator, Social Worker, and a Consultant Psychiatrist from the Tier 3 CAMHS service. Through my visits to a preschool nursery and primary school I was able to observe differences between children’s levels of cognitive development and the importance of play. I attended a School Network meeting that included presentations on bullying, interventions such as ‘Circle of Friends’ and Social Skills programmes such as ‘Dinosaur School’. I also attended seminars at the Institute of Psychiatry on Looked After Children and Child Art Psychotherapy. A one-day course at the Maudsley on recent developments in Cognitive Therapy with children and adolescents furthered my knowledge on the application of this approach to this client group. I attended several Psychology Department meetings including a presentation on the revised Parent Adviser Training Manual, and was also able to observe the process and proceedings of a child protection case conference.
The Assessment and Intervention of a fourteen-year-old girl presenting with Social Phobia using a Cognitive Behavioural model.

Presenting Problem
Vicky, a fourteen year old black adolescent was referred to the Tier 2 Community Child and Family Service by her General Practitioner. She presented with problems relating to bullying she had experienced at school. Vicky reported to be particularly fearful of social situations, and was very worried about what others would say about her and how they would judge her.

Assessment
Both Vicky and her father, Richard who accompanied her to the sessions, were involved in the initial assessment. During the clinical interview information was obtained concerning the onset and development of the problem, and the issue of race as a precipitating factor raised. Details regarding Vicky’s family relationships were obtained using a genogram, and information relating to developmental history acquired, aided by the use of a visual ‘time line’. In addition two standardised measures were administered namely the Spence Children’s Anxiety Scale (SCAS; Spence, 1994), and the Birleson Depression Scale (Birleson, Hudson, Gray-Buchanan & Wolff, 1987).

Formulation
Vicky’s difficulties were initially formulated in terms of social phobia, the onset of which is typically gradual and occurring in teenage years (Clark, 1999). Clark and Wells’ (1995) cognitive model of social phobia was drawn upon. It was hypothesised that Vicky’s experiences of being bullied led to the development of certain negative beliefs such as ‘I’m unlikeable/different’. Thus certain assumptions were held which lead Vicky to make particular appraisals about social situations, typically how she would perform in the situation and what others would think and say about her. Ambiguous social cues would be interpreted as signs that others had made a negative evaluation of her, which caused her much distress. This distress was maintained by
several factors which served to prevent her negative appraisals and beliefs being disconfirmed. This included the processing of herself as a social object, whereby her attention was shifted inwards and she used internal information to infer how she looked to others; somatic and cognitive symptoms of anxiety which fuelled her negative cognitions; pre and post event processing, in which she anticipated what she thought might happen prior to an event, then conducted a post mortem of it afterwards, as well as using several safety behaviours and avoidance.

**Intervention**

The intervention was based upon a cognitive-behavioural approach for social phobia utilising Clark & Well’s (1995) model. However the treatment approach as advocated by Clark & Wells (1995) was flexibly applied given the time available for intervention, Vicky’s specific goals, and also consideration of the systems of which she was a part, such as her family and the school she attended.

Six intervention sessions were offered in line with standard departmental procedure. Psycho-education occurred initially to socialise Vicky to the cognitive-behavioural model, and a visual conceptualisation of Vicky’s difficulties based upon Clark and Wells’ (1995) model of social phobia constructed and a recent example worked through. The use of metaphor was used throughout to help convey information (Stallard, 2002) and Vicky acted as an ‘experimenter’, testing things out and generating new information. Socratic questioning, behavioural experiments, and thought records were used to aid cognitive restructuring. Vicky was encouraged to act as a detective, looking for clues, namely evidence for and against her thoughts, and the downward arrow technique used to explore meaning. A positive data log was also used to add permanence to ‘discounted’ information. Integral to the intervention was communication with Vicky’s father and the secondary school.

**Outcome**

Following the intervention Vicky was able to report several changes. Vicky was going out more and entering into social situations in which it was likely that other teenagers would be present, and had recently joined a swimming club. She also began to travel on buses, which she had not done for over a year. She regarded the
intervention as 'very helpful' however felt it was 'early days' as she remained preoccupied about what others thought of her. This was reflected in the repeat measures remaining relatively stable. A reformulation is offered and discussion given relating to the duration of treatment in light of the evidence base available, as well as other factors which were considered to be pertinent to this case.

(A comprehensive reference list can be found in the appropriate case report in Volume II)
Older People Placement Summary

Placement details
Supervisor: Dr Ian Kneebone, Consultant Clinical Psychologist.
NHS Trust: Guildford and Waverley NHS Primary Care Trust.
Base: Milford Hospital, Milford, Surrey.

Summary of experience

Overview
This placement provided an opportunity to develop my skills and knowledge in neuropsychological testing, group work and rational-emotive therapy as well as consolidate my abilities in cognitive-behavioural assessment, formulation and intervention. This occurred in conjunction with an increasing awareness of some of the adaptations needed (e.g. due to sensory impairments) to work successfully with this client group. This placement also gave me a good insight into some of the benefits and challenges of applying psychology theories within a multi-disciplinary team in a medical context.

Models
This placement focused on the application of cognitive behavioural as well as rational emotive therapy. It also provided an opportunity to develop my skills and knowledge in neuropsychological/psychometric testing. My involvement in group work also increased my knowledge regarding group processes and group dynamics.

Settings
The placement was based within a multi-disciplinary team in a physical rehabilitation hospital comprising an assessment and rehabilitation day unit, and several in-patient wards. Clinical work was undertaken in a range of settings including: the day hospital, in-patient wards and client homes, as well as a day centre for people with dementia.
Clinical skills and experience

Clinical experience encompassed working with males and females (age range 72-86) from a predominantly white, British background, as well as their families, carers and the multi-disciplinary team on a range of presenting problems including: depression, loss/bereavement, physical health problems, anxiety, fear of falling and dementia. Clients were also seen for cognitive testing with presenting difficulties such as memory problems, stroke, left sided visual neglect, dementia and depression. A range of psychological assessment procedures were used (e.g. WAIS-III, RBMT, CAMCOG, WTAR, BASDEC, Hayling & Brixton, RBANS, IQCODE, items from the BIT). In addition a multi-disciplinary pain management group for older people was conducted and evaluated using a range of measures (e.g. MPQ, CSQ, HADS). A follow-up session was also devised, implemented and evaluated. A reminiscence group for older people with dementia who attended an Alzheimer’s Society day centre was also developed and conducted.

Meetings, observations and seminars

I attended various seminars on topics such as Parkinson’s disease, the role of the Psychologist in Physical Rehabilitation, and Stroke: causes and prevention. I also attended presentations at the Psychology meetings on matters such as race and ethnicity issues in Older People, and presented at this forum a talk on Older People and Suicide. In addition I gave several case presentations within joint supervision. My knowledge regarding the procedures involved in protecting vulnerable adults was enhanced through attending a multi-agency workshop. In order to further my understanding of the roles and skills of other professionals in this setting I met with a Matron, Ward Sister, SHO, Physiotherapist, OT, SALT, Care Manager and Coordinator of Intermediate Care Services. In order to explore some of the similarities and differences between this setting and that of a community mental health team for the elderly I attended a referral meeting and met with the Consultant Clinical Psychologist from the local CMHT(E).
Older People Case Report Summary

A Multi-disciplinary Pain Management Group for Older People experiencing Chronic Pain

Presenting Problem
Several referrals had been made to the multi-disciplinary team (MDT) at a day hospital regarding older people who were experiencing chronic pain. Given the evidence base, as discussed below, it was decided to treat these older people within a group setting as opposed to individually.

Assessment
Five individuals were assessed for inclusion into a pain management group. Certain inclusion criteria were applied e.g. individuals needed to be able to hear at normal volume, and see over 6 feet, thus the presence of sensory impairments was particularly considered as this may have affected individuals ability to engage in the group. In addition to an assessment interview, certain measures were administered: namely the Pain Coping Strategies Questionnaire (Rosenstiel & Keefe, 1983); the McGill Pain Questionnaire (Melzack, 1975); and the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) in order to aid outcome evaluation. The Abbreviated Mental Test Score (Hodkinson, 1972) was used as a one-off screen to detect any possible cognitive impairment, and therefore identify individuals who were not appropriate for the group. Four individuals were considered suitable for inclusion into the group: Rachel, Jennifer, Doreen & Judy, who were all of white British ethnic origin and aged from 72-86 years.

Formulation
A group formulation was constructed. This was influenced by Melzack and Wall's (1965) gate control theory of pain, and the biopsychosocial approach to conceptualising chronic pain for which there is much evidence (Turk, 1996). It was hypothesised that individuals held certain beliefs about their pain which impacted on their mood, behaviour and the pain itself. Particular attention was focused upon the role of self-efficacy, decreased physical ability and pain avoidance in the maintenance
of chronic pain. It was hypothesised that for these older people pain had been predominantly viewed from a biomedical perspective, with medication being the primary form of management. By taking a biopsychosocial perspective intervention was to be targeted at various psychosocial and physical factors. Furthermore given the social element of the group environment it was also conceptualised that group members would benefit from some of the group processes which have been regarded as therapeutic such as 'imparting information', 'instillation of hope', 'universality', and 'group cohesiveness' (Yalom, 1985).

**Intervention**

Several studies have shown that multi-disciplinary group based treatments that employ a cognitive-behavioural approach are effective in reducing pain and enhancing psychological and physical functioning within older people (e.g. Cutler, Fishbain, Rosomoff & Rosomoff, 1994). Therefore in view of the evidence base such a group was conducted. Four women, and one male carer (spouse) attended the pain management group, which comprised 8 weekly sessions lasting 2 hours, and involved psychology, nursing and physiotherapy input. Each session typically involved a recap/ homework review, presentation and discussion of material facilitated through pair work, group brainstorms as well as group quizzes to ensure the active participation of group members as much as possible, physiotherapy and relaxation exercises, and also the setting of homework at the end of each session. A tape incorporating the relaxation exercises was provided, and handouts supplied at the end of every session summarizing the material covered.

The psychological component of the group included: the stress response; thoughts, feelings, behaviour and pain - the 'vicious circle' concept; goal setting; pacing, distraction; as well as various relaxation exercises such as diaphragmatic breathing and 'relaxing the mind'. Other elements involving the MDT members included information on the spine, posture, seating, lifting and bending, medication, physiotherapy exercises, and flare ups/set backs.

Early on in the group there was a strong sense of similarity or 'universality' between group members (Yalom, 1985), in that for them pain 'controlled everything'.
Through psycho-education, and information being imparted in a way that instilled hope, group members where able to utilise cognitive behavioural principles to enhance their cognitive and behavioural pain coping strategies. As the group progressed, a strong sense of group cohesion emerged, and attendance remained high.

**Outcome**

During session 8 group members completed the baseline measures, as well as a feedback form. Much positive feedback was obtained, for example Judy commented about the group: 'I walk on the grass with more confidence but not on the road. I can sleep better, and don't worry so much when I wake early. It has been a great help to me'. On the repeat administration of the baseline measures several positive changes were noted. Reported levels of behavioural activities had increased for all members, and the use of other adaptive strategies such as diverting attention was improved in the majority of group members. Other less helpful coping strategies such as catastrophizing were reduced. Generally these gains were maintained at follow up 2 months later, with further improvements in areas such as mood occurring for some group members. In addition individuals had continued to make progress in meeting the goals they had set themselves during the group. The effectiveness of this intervention is discussed further drawing upon biopsychosocial and group process factors. A critique of the work conducted, and discussion of some of the difficulties encountered is also given.

*(A comprehensive reference list can be found in the appropriate case report in Volume II)*
Placement details


Supervisor: Dr Susan Childs, Clinical Psychologist, Dr Selen Osman, Clinical Neuropsychologist.

NHS Trust: St Georges Healthcare NHS Trust.

Base: Wolfson Neurorehabilitation Centre, Wimbledon.

Summary of experience

Overview

Considerable experience was gained in both individual and group work with individuals who presented with chronic pain and as a consequence of Traumatic Brain Injury (TBI)/stroke and other neurological concerns on this split placement. In conjunction with the original presenting issues, individuals had a range of associated difficulties such as speech and language problems, reduced attention span, and were prone to fatigue. This necessitated adapting my practice to meet the needs of the client, for example through having shorter and more frequent sessions. In this placement I developed my experience of organisational work through producing a referral to psychology form for the Pain Management Assessment days, which following piloting was incorporated into practice. An important consideration when working with this client group was the diverse social and cultural backgrounds which individuals came from.

Models

Several models were utilised during this placement. For patients presenting with chronic pain a biopsychosocial perspective was adopted and a predominantly CBT approach taken. However for patients who presented in the neuro-rehabilitation and neuro-diagnostic service models comprised CBT, Systemic, Behavioural as well as Neuropsychological models emanating from the relationship between brain and behaviour.
Settings
This placement was based within a specialist Neuro-rehabilitation centre. Clinical work was undertaken in out-patient clinics, day-patient and in-patient settings.

Clinical skills and experience
Clinical experience involved working with males and females (age range 17-68 years) from a range of ethnic backgrounds, as well as their families and the multi-disciplinary team (MDT), on a range of presenting problems. These included adjustment issues following TBI/stroke; chronic pain present in single and multiple sites such as head, neck and back, which was co-morbid with psychological problems such as depression, anxiety and obsessive-compulsive disorder as well as physical health concerns. Individuals were also seen for neuropsychological assessment as part of the neuro-rehabilitation as well as neuro-diagnostic service following difficulties in areas such as memory, attention, information processing and executive functioning. A range of psychological assessment tools were used throughout the placement (e.g. Pain diary, HADS, WASI, WTAR, BADS, BDI-II, BAI, WAIS-III, WMS-III, VASES, Token Test, Kaplan Baycrest, Rey Fifteen Items Test, items from Doors & People). As well as direct work with individuals and their systems, group work formed a significant part of the placement. A Thoughts and Feelings group was conducted jointly with my supervisor as part of the intensive Cognitive Rehabilitation Group Programme. Furthermore I co-facilitated and ran independently many of the Psychology sessions from the 3 week rolling Pain Management Programme.

Meetings, observations and seminars
During this placement I attended two training days; one on Stroke; the other on Goal Setting, at the Atkinson Morley Wing in St Georges Hospital. I met with several members of the MDT including OT, Physiotherapy, SALT, Business Manager of the service, a Consultant Clinical Psychologist in pain management, and a Consultant Neuropsychologist working in an acute hospital who provided a neuro-diagnostic service. As well as regularly attending the goal planning meetings of patients with whom I was working, I attended some trainers meetings to discuss issues arising from the group sessions of the Cognitive Rehabilitation Group Programme, e.g. group dynamics, and met with members of the MDT regarding the content of a pain
management presentation. Consequently I presented the psychological component of the Wolfson Pain Management Programme to a large forum of medical colleagues.
Neuropsychological Assessment of a fifty-three year old man presenting with Memory problems

Presenting Problem
James, a fifty-three year old man of white British ethnic origin, was referred by his Consultant Neurologist. The referral requested a detailed cognitive assessment in view of concerns about James’ memory. James described difficulties remembering conversations and noted that he would say things to other people that he had “already said 10 minutes ago”. James also spoke about having difficulty reading, in that he would forget what he had just read and so would have to read a page “over and over again”. The assessment was to be used to aid diagnosis.

Assessment
Clinical interview with James, and his wife, Lucy occurred in order to elucidate the history of James’ memory problems. In addition, information on James’ personal history including familial, educational and occupational background, as well as medical and psychiatric history were obtained to inform the initial hypotheses.

Hypotheses
Based on the information obtained at interview, as well as a thorough review of the literature, several hypotheses were generated regarding James’ memory difficulties. It was considered that James’ may have a neuropsychological profile consistent with a type of dementia; specifically alcohol-induced dementia, Alzheimer’s disease or vascular dementia; poorly controlled diabetes; or depression. The neuropsychological profiles that are characteristic of these conditions are considered.

Neuropsychological Assessment
The rationale for the range of neuropsychological measures used is discussed, and details regarding James’ behaviour during the assessment is provided. The following tests and questionnaires were employed during the assessment:

- Wechsler Adult Intelligence Scale – Third Edition (WASI-III)
Summary of Neuropsychological findings
James’ current level of intellectual functioning, as assessed by the WAIS-III fell within the average range. His premorbid estimate of cognitive functioning similarly fell within the average range. However there was a statistically significant difference between these scores, which suggested a slight change in general levels of cognitive functioning. Differences were not significant between James’ verbal and non-verbal overall abilities. However his verbal comprehension and reasoning abilities were significantly better than his working memory, nonverbal reasoning abilities, and his speed of processing visual information. James’ recall of auditory information immediately after it had been presented fell in the average range. Following a delay of approximately 30-minutes his recall of auditory-based information was found to be in the low average range. These scores differed significantly. James’ recall of visually presented information both immediately and after a short delay was in the extremely low range. Executive functioning ability was in the low average range. Anxiety was in the mild range and his score for depression was in the normal range. In summary, the results of the assessment suggest that James had significant memory impairment, particularly within the visual modality.

Formulation
The most likely condition to account for James’ neuropsychological profile appeared to be alcohol-induced dementia, exacerbated by the effects of poorly controlled diabetes. Historical information in the form of his previous excessive alcohol intake over many years, coupled with the more visual nature of his memory deficits and slowed processing speed appeared to point to a dementia of a more alcohol induced nature. However given that James had multiple risk factors for vascular dementia, such as hypertension, diabetes and previous excessive alcohol intake, it was possible that small and repeated infarcts in different brain sites may have given rise to a profile
such as this. On the basis of neuropsychological testing alone it was not possible to
differentiate clearly between these two types of dementia. Reasons for discounting
the other hypotheses are also provided.

**Intervention**

The results of the assessment were fed back to James, and his wife Lucy, and a
possible diagnosis of dementia provided. In addition as they were both concerned
about the feasibility of employment for James this was considered alongside the feed
back of the results. Furthermore other means of support were discussed such as
referral to a Community Rehabilitation Team as a means of providing practical
assistance relating to the impairments found.

In order to detect the nature and extent of any further cognitive decline a re-
assessment was recommended in approximately 12 months time. Further medical
investigation such as an MRI scan was also considered necessary. A report detailing
the assessment, results and recommendations was provided to the referrer.

Difficulties encountered, such as access to James' medical records, were also
provided in the form of a critique of the work undertaken.

*(A comprehensive reference list can be found in the appropriate case report in
Volume II)*
Child & Family Specialist Placement Summary

Placement details
Dates: April 2004 to September 2004
Supervisor: Dr Louise Paque, Clinical Psychologist
NHS Trust: Ashford & St Peters NHS Trust
Base: Merlin Children’s Unit, Ashford Hospital, Ashford, Middlesex & Child & Adolescent Mental Health Service, St Peter’s Hospital, Chertsey, Surrey.

Summary of experience

Overview
At the time of writing 4 months of the 6-month placement have been completed. To-date this placement has provided me with an opportunity to work systemically and apply therapies such as Narrative Therapy and Solution-Focused Therapy. I have developed my experience of providing interventions that are brief and short-term as part of a Primary Mental Health Team (PMHT), as well as providing longer interventions for more complex cases within a Child and Adolescent Mental Health Service (CAMHS). Furthermore I was able to develop my experience of working indirectly through providing consultation to children, adolescents and their families.

Models
This placement allowed me to develop my skills of using Narrative Therapy, as well as Solution-Focused Therapy. Other models utilised on this placement included Systemic, CBT and Behavioural.

Settings
The placement was based within a CAMH service which encompassed a Primary Mental Health Team. Clinical work was undertaken in various settings including the clients’ home, out-patient clinics within the PMHT and CAMHS, and schools within the area.
Clinical skills and experiences
Clinical experience involved working directly and indirectly with male and female children and adolescents (age range 4-15) from a predominantly white, British background, as well as their parents on a range of presenting problems. This included depression, post-traumatic stress disorder following physical assault, family relationship difficulties, sleep problems, travel phobia, anxiety/obsessional behaviour, and feeding difficulties occurring in a child with severe learning disabilities. Working indirectly enabled me to develop my consultation skills with families and other professionals. I also developed a greater insight into the role of the School Nurse within an enuresis clinic, and the role of family therapy within CAMHS. Here I formed part of a reflecting team both in the room and behind a one-way screen. Formal measures used on this placement included the BDI-II, and the Impact of Events Scale.

Meetings, observations and seminars
In order to understand the 'systems' within the placement I met with a variety of professionals including a Clinical Nurse Therapist, Senior Mental Health Worker, Senior Social Work Practitioner, CAMHS Community Development Manager, Primary Mental Health Worker, Art Therapist, Psychotherapist, School Nurse and a Clinical Psychologist working within a Child Assessment Service for under 5s with complex problems and developmental delay. My awareness of Tier 4 provision was heightened through visiting a newly opened in-patient unit. I attended several Psychology meetings, and consultation meetings with psychiatry during the placement, as well as several Psychotherapy, and CBT, supervision groups. I also attended planning meetings, one of which was related to the development of an emotional literacy programme within schools in the locality, the other concerning referrals received within a multi-agency child assessment service. In addition I attended a one-day conference on 'Solution-Orientated Brief Therapy with Children & Adolescents: Imagination, Play and Possibilities', as well as the South Thames SIG on 'CAMHS Tier 2 Services – Models of working and implications for Clinical Psychologists. Furthermore I attended 2 educational half days within CAMHS on the NICE guidelines for eating disorders and the diagnostic interview for social and communication disorders (DISCO).
RESEARCH DOSSIER

Overview
This section includes the service related research project completed on a clinical placement in year one, the group qualitative research project completed in year two, and the major research project completed in year three. The research logbook is included in this dossier, which demonstrates the research skills and experience acquired over the course of training.
Service Related Research Project

Retrospective analysis of women assessed for a survivors of sexual abuse group: who attends and who drops out?

June 2002
Year 1
Acknowledgements

Thanks go to James Murray, my research supervisor, as well as Maeve Crowley, my field supervisor, and Teresa Greenfield and Mandy Gray, the group facilitators, for their help with this study. I am also grateful to the participants who were assessed for the survivors group, who made this research possible.
Abstract

Title: Retrospective analysis of women assessed for a survivors of sexual abuse group: who attends and who drops out?

Objective: Of the empirical studies which exist, there is some evidence to suggest that group therapy can be a beneficial treatment for adult women survivors of child sexual abuse. As with any form of therapy attrition can be a problem. Certain features related to the abuse and the individuals' current supports have been found to affect attendance. This study aimed to provide a profile of women, who following assessment, attend and complete (completers) or dropout (dropouts) of a survivors of sexual abuse group in one adult mental health service.

Method: Data was retrospectively obtained from case notes held. All women who had attended an assessment interview and were subsequently offered a place in the group were included (n=83). Qualitative information was categorised and coded. Inter-rater reliability was analysed, and a Cohen's kappa of 0.95 found.

Results: Chi-square analysis revealed a significant difference between completers and dropouts in terms of their age at assessment, the abusers identity and whether interpersonal effects arising from the abuse had been reported at the time of assessment.

Conclusion: It would appear that there are some important differences between women who dropout and those who complete a survivors of sexual abuse group in the adult mental health service studied. Methodological limitations, along with implications and recommendations for the service are discussed.
Introduction

Little consensus exists within the psychological literature regarding the prevalence of child sexual abuse (CSA) amongst adult women. Fergusson and Mullen (1999) indicate that the majority of studies suggest a prevalence rate of between 15-30%, although Wyatt (1985; cited in Ussher & Dewberry 1995) reported a figure as high as 62%. Watson, Scott & Ragalsky (1996) note that in spite of this little specific provision has been made in adult mental health services to treat women survivors, even though the long-term effects of CSA have been well documented (Christo, 1997; Cahill, Llewelyn & Pearson, 1991; Brown & Finkelhor, 1986).

Of the many treatments for CSA few have had empirical validation (Fergusson & Mullen, 1999). One such treatment where studies are now emerging is that of group therapy, which has clinically been regarded as being particularly beneficial, as it allows the individual to meet other survivors and thus facilitates a greater resolution in issues such as secrecy, shame and self-blame (Herman & Schatzow, 1984; cited in Watson et al., 1996). Alexander, Neimeyer, Follette, Moore and Harter (1989) conducted the first controlled outcome study evaluating the effectiveness of group therapy for women sexually abused as children, and found that compared to a wait list control, group treatments were significantly more effective in reducing depression and distress. Other studies claiming similar effects have followed (e.g. Morgan & Cummings, 1999; Saxe & Johnson, 1999).

One feature of group work is of attrition, with individuals often not completing the course of treatment. This issue has been explored with Blake-White and Kline (1985: cited in Cahill et al., 1991) reporting a drop-out rate of 37% up to and including the fifth session. Fisher, Winne and Ley (1994) note that there is a need to discover what differentiates individuals who drop-out from those who do not, in order to facilitate the most appropriate treatment. They found women who dropped out were more likely to have been physically abused as children, and to have been sexually abused solely by individuals within the family, compared to women who completed group therapy. Other factors influencing outcome included being involved in a relationship with at least one significant other (Goodman & Nowak-Scibelli, 1985). As well as implications for the individual, early dropout can have implications for the service,
through for example the inefficient use of professionals’ time (Keen, Blakey & Peaker, 1996).

An adult mental health service, which offers time-limited group therapy for adult women who have been sexually abused as children, was the setting for this study. This group is facilitated by 2 female therapists, an Occupational Therapist (OT) and a Community Psychiatric Nurse (CPN), who receive supervision from a Consultant Clinical Psychologist following each session. The survivors of sexual abuse group began in 1996. Since then 9 groups have run in total. These comprise 10 weekly sessions of one and a half hours. No outcome data is currently collected and no major analysis has been conducted on these groups to-date.

Aims
The aims of this study are two-fold: Firstly to provide information as to the number and profile of women who have been assessed for the survivors of sexual abuse group therapy since its inception in 1996. Secondly to examine whether women who then drop-out at any point following this assessment (dropouts) differ from women who complete the group therapy (completers) on variables such as abuse history and support available as highlighted by the research literature. Additionally service factors, such as referral source and length of wait between assessment and group start, will be explored to establish whether this also affects attrition.

Taken together these aims intend to improve the understanding of the client population for this particular service in terms of who is being assessed and subsequently attending and completing or dropping out of the survivors groups. This is intended to provide a basis for further audit and research, as well as informing future treatment planning.

Main Hypotheses
1) There will be a significant difference in the abuse history of women who complete the group compared to women who drop out of the group.
2) There will be a significant difference in the social support of women who complete the group compared to women who drop out of the group.
Method

Design
The design of this study was non-experimental and involved a retrospective analysis of case notes.

Sample
All women who attended an assessment interview for the survivors of sexual abuse group, and were offered a place in the group were included (n=83). Completers were defined as individuals who attended half or more of the group, that is, between 6 to 10 sessions (n=46). Dropouts comprised those who attended less than half of the sessions (n=37). This definition was used to facilitate comparison between Blake-White & Kline (1985) findings as described earlier.

Materials and Procedure
Data was initially collected from clinical hand-written notes made by one of the co-therapists at the assessment interview. From the fourth survivors group onwards an assessment form was devised and routinely used. Much of the data in the study was therefore obtained from this form. A copy is listed in Appendix A.

At the initial stage of the study discussion took place with the Consultant Clinical Psychologist who identified key variables of interest to the service. Categories were largely generated from the assessment form, as well as the data itself, and the research literature. Codes were then devised for the data. The categories and codes were distributed to the group facilitators and Psychologist to allow for modification following feedback. The codes and categories that were used are listed in Appendix B and C. Also at an early stage the Clinical Audit and Research Manager of the Trust was contacted, and as the study did not necessitate a proposal to the ethics committee, a clinical audit protocol form was completed (see Appendix D).

As much of the data was in a qualitative format initially and subsequently categorised and coded, an independent rater was used to establish reliability.
Results

Demographic and Service-related details.

Chi-square was used to compare the dropouts and completers on the categorical variables. No significant differences were found between the two groups in terms of marital status ($\chi^2 (2, N=75)=0.78, p=.67$), taking anti-depressants ($\chi^2 (1, N=57)=3.63, p=.05$), currently working ($\chi^2 (1, N=68)=2.76, p=.09$), or having children ($\chi^2 (1, N=79)=0.28, p=.59$). Due to the small numbers involved it was not possible to conduct a chi-square analysis for the variables of location, referral source or taking anti-psychotics. Descriptive statistics are given in Table 1.

Table 1: Demographic and Service-related details

<table>
<thead>
<tr>
<th></th>
<th>All N (Valid %)</th>
<th>Dropouts N (Valid %)</th>
<th>Completers N (Valid %)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age in years</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>N=83, M=33, SD=7.9,</td>
<td></td>
<td>N=28, M=30, SD=7.8,</td>
<td>N=37, M=35, SD=7.4,</td>
</tr>
<tr>
<td>Range=18-52</td>
<td></td>
<td>Range=18-47</td>
<td>Range=22-52</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>26 (34.7)</td>
<td>10 (29.4)</td>
<td>16 (39)</td>
</tr>
<tr>
<td>Married/Co-habiting</td>
<td>28 (37.3)</td>
<td>14 (41.2)</td>
<td>14 (34.1)</td>
</tr>
<tr>
<td>Divorced/Separated</td>
<td>21 (28)</td>
<td>10 (29.4)</td>
<td>11 (26.8)</td>
</tr>
<tr>
<td><strong>Location</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Next major town&gt;8 miles</td>
<td>17 (21.3)</td>
<td>9 (25.7)</td>
<td>8 (17.8)</td>
</tr>
<tr>
<td>Same town as group</td>
<td>56 (70)</td>
<td>23 (65.7)</td>
<td>33 (73.3)</td>
</tr>
<tr>
<td>Other places</td>
<td>7 (8.8)</td>
<td>3 (8.6)</td>
<td>4 (8.9)</td>
</tr>
<tr>
<td><strong>Anti-Depressants</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>24 (42.1)</td>
<td>7 (28)</td>
<td>17 (53.1)</td>
</tr>
<tr>
<td>No</td>
<td>33 (57.9)</td>
<td>18 (72)</td>
<td>15 (46.9)</td>
</tr>
<tr>
<td><strong>Anti-Psychotics</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>7 (12.3)</td>
<td>4 (16)</td>
<td>3 (9.4)</td>
</tr>
<tr>
<td>No</td>
<td>50 (87.7)</td>
<td>21 (84)</td>
<td>29 (90.6)</td>
</tr>
<tr>
<td><strong>Working</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>28 (41.2)</td>
<td>9 (30)</td>
<td>19 (50)</td>
</tr>
<tr>
<td>No</td>
<td>40 (58.8)</td>
<td>21 (70)</td>
<td>19 (50)</td>
</tr>
<tr>
<td><strong>Children</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>58 (73.4)</td>
<td>26 (76.5)</td>
<td>32 (71.1)</td>
</tr>
<tr>
<td>No</td>
<td>21 (26.6)</td>
<td>8 (23.5)</td>
<td>13 (28.9)</td>
</tr>
<tr>
<td><strong>Referral source</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CPN</td>
<td>38 (52.8)</td>
<td>18 (54.5)</td>
<td>20 (51.3)</td>
</tr>
<tr>
<td>Psychologist</td>
<td>17 (23.6)</td>
<td>9 (27.3)</td>
<td>8 (20.5)</td>
</tr>
</tbody>
</table>

3 Place names are not used to ensure anonymity of the service.
Figure 1 shows the total number of sessions attended by the sample following assessment.

An independent samples t-test was used for the parametric data. No significant differences were found for the 'length of wait' variable (t (66)=0.01, p=.98), however there was a significant difference between the two groups on the 'age at assessment' variable (t (63)=2.58, p=<.05).

Support
Dropouts did not differ significantly from completers on any of the support variables: support from partner ($\chi^2 (1, N=70) = 1.94, p=0.16$), support from family ($\chi^2 (1, N=70) = 1.87, p=0.17$), support from friend ($\chi^2 (1, N=70) = 0.0, p=0.94$), support from
professionals ($\chi^2 (1, N=70) = 1.41, p=0.23$). Descriptive details can be found in
Table 2.

Table 2: Support

<table>
<thead>
<tr>
<th></th>
<th>All</th>
<th>Dropouts</th>
<th>Completers</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N (Valid %)</td>
<td>N (Valid %)</td>
<td>N (Valid %)</td>
</tr>
<tr>
<td>Support from partner</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>30 (42.9)</td>
<td>10 (33.3)</td>
<td>20 (50)</td>
</tr>
<tr>
<td>No</td>
<td>40 (57.1)</td>
<td>20 (66.7)</td>
<td>20 (50)</td>
</tr>
<tr>
<td>Support from family</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>25 (35.7)</td>
<td>8 (26.7)</td>
<td>17 (42.5)</td>
</tr>
<tr>
<td>No</td>
<td>45 (64.3)</td>
<td>22 (73.3)</td>
<td>23 (57.5)</td>
</tr>
<tr>
<td>Support from friends</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>26 (37.1)</td>
<td>11 (36.7)</td>
<td>15 (37.5)</td>
</tr>
<tr>
<td>No</td>
<td>44 (62.9)</td>
<td>19 (63.3)</td>
<td>25 (62.5)</td>
</tr>
<tr>
<td>Support from professionals</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>12 (17.1)</td>
<td>7 (23.3)</td>
<td>5 (12.5)</td>
</tr>
<tr>
<td>No</td>
<td>58 (82.9)</td>
<td>23 (76.7)</td>
<td>35 (87.5)</td>
</tr>
</tbody>
</table>

**Qualitative analysis**

Qualitative data was categorised and coded. A sample of this was analysed by an
independent rater. Inter-rater reliability was calculated using Cohen’s kappa (Fleiss,
1981). Fleiss (1981) states that kappa coefficients greater than 0.75 represent
excellent agreement. A Cohen’s kappa of 0.95 was calculated.
Abuse history

Dropouts did not differ significantly from completers on any of the following variables: 'intercourse' ($\chi^2 (1, N=80) = 0.38, p=.53$), 'touching' ($\chi^2 (2, N=80) = 3.65, p=.16$), 'physical abuse' ($\chi^2 (1, N=80) = 0.00, p=.92$), 'disclosed at the time' ($\chi^2 (1, N=80) = 0.06, p=.80$). The identity of abuser variable was recoded to facilitate chi-square analysis, and was found to be significant ($\chi^2 (1, N=80) = 7.17, p<.01$). It was not possible to conduct a chi-square analysis for 'number of abusers', 'other abuse reported', and 'authorities notified' due to the small number of participants falling into some of the categories. Descriptive statistics are shown in Table 3.

Table 3: Abuse history details

<table>
<thead>
<tr>
<th></th>
<th>All (Valid %)</th>
<th>Dropouts (Valid %)</th>
<th>Completers (Valid %)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N=70, M=7.6, SD=3.1</td>
<td>N=30, M=7.7, SD=3.2</td>
<td>N=40, M=7.5, SD=3.1</td>
</tr>
<tr>
<td>Age abuse began in years</td>
<td>N=57, M=5.6, SD=4.1</td>
<td>N=24, M=5.7, SD=3.7</td>
<td>N=33, M=5.6, SD=4.5</td>
</tr>
<tr>
<td>Intercourse reported</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>38 (47.5)</td>
<td>18 (51.4)</td>
<td>20 (44.4)</td>
</tr>
<tr>
<td>No</td>
<td>42 (52.5)</td>
<td>17 (48.6)</td>
<td>25 (55.6)</td>
</tr>
<tr>
<td>Touching reported</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>34 (42.5)</td>
<td>19 (54.3)</td>
<td>15 (33.3)</td>
</tr>
<tr>
<td>Included masturbation</td>
<td>13 (16.3)</td>
<td>4 (11.4)</td>
<td>9 (20)</td>
</tr>
<tr>
<td>No</td>
<td>33 (41.3)</td>
<td>12 (34.3)</td>
<td>21 (46.7)</td>
</tr>
<tr>
<td>Other abuse reported</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Photos taken</td>
<td>3 (3.8)</td>
<td>1 (2.9)</td>
<td>2 (4.4)</td>
</tr>
<tr>
<td>Oral sex</td>
<td>5 (6.3)</td>
<td>2 (2.7)</td>
<td>3 (6.7)</td>
</tr>
<tr>
<td>Bribes</td>
<td>3 (3.8)</td>
<td>1 (2.9)</td>
<td>2 (4.4)</td>
</tr>
<tr>
<td>Threats</td>
<td>10 (12.5)</td>
<td>4 (11.4)</td>
<td>6 (13.3)</td>
</tr>
<tr>
<td>Combination</td>
<td>6 (7.5)</td>
<td>1 (2.9)</td>
<td>5 (11.1)</td>
</tr>
<tr>
<td>None</td>
<td>53 (66.7)</td>
<td>26 (74.3)</td>
<td>27 (60)</td>
</tr>
<tr>
<td>Number of abusers</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>One</td>
<td>54 (67.5)</td>
<td>25 (71.4)</td>
<td>29 (64.4)</td>
</tr>
<tr>
<td>Two</td>
<td>16 (20)</td>
<td>6 (17.1)</td>
<td>10 (22.2)</td>
</tr>
</tbody>
</table>
### Effects of abuse

Responses listed under 'effects' on the assessment form were coded into 6 categories (emotional, interpersonal, sexual, behavioural, cognitive and physical) as defined by Sanderson (1990). Details regarding the specific nature of each categories content can be found in Appendix C, alongside examples to illustrate how the responses were coded. An additional 'suicide attempt reported' category which emerged through the data is also included. Dropouts did not differ significantly from completers on any of the following reported effects: emotional ($\chi^2 (1, N=80)=0.68, p=.40$), sexual ($\chi^2 (1, N=80)=0.20, p=.64$), behavioural ($\chi^2 (1, N=80)=0.00, p=.93$), cognitive ($\chi^2 (1, N=80)=0.26, p=.60$), physical ($\chi^2 (1, N=80)=2.16, p=.14$). No significant differences were found with the 'suicide attempt reported' variable ($\chi^2 (1, N=80)=0.00, p=1.0$). However there was a significant difference between the two groups on the 'interpersonal effects reported' variable ($\chi^2 (1, N=80)=12.23, p=.001$). Descriptive details are given in Table 4.

---

To use chi-square analysis this variable was recoded: father, stepfather, brother and other male relation were combined to form a 'solely within family' category. The other two categories were also combined.
Table 4: Effects of abuse

<table>
<thead>
<tr>
<th></th>
<th>All N (Valid %)</th>
<th>Dropouts N (Valid %)</th>
<th>Completers N (Valid %)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Emotional effects reported</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>65 (81.3)</td>
<td>27 (77.1)</td>
<td>38 (84.4)</td>
</tr>
<tr>
<td>No</td>
<td>15 (18.8)</td>
<td>8 (22.9)</td>
<td>7 (15.6)</td>
</tr>
<tr>
<td><strong>Interpersonal effects reported</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>49 (61.3)</td>
<td>29 (82.9)</td>
<td>20 (44.4)</td>
</tr>
<tr>
<td>No</td>
<td>31 (38.8)</td>
<td>6 (17.1)</td>
<td>25 (55.6)</td>
</tr>
<tr>
<td><strong>Sexual effects reported</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>25 (31.3)</td>
<td>10 (28.6)</td>
<td>15 (33.3)</td>
</tr>
<tr>
<td>No</td>
<td>55 (68.8)</td>
<td>25 (71.4)</td>
<td>30 (66.7)</td>
</tr>
<tr>
<td><strong>Behavioural effects reported</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>37 (46.3)</td>
<td>16 (45.7)</td>
<td>21 (46.7)</td>
</tr>
<tr>
<td>No</td>
<td>43 (53.8)</td>
<td>19 (54.3)</td>
<td>24 (53.3)</td>
</tr>
<tr>
<td><strong>Cognitive effects reported</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>25 (31.3)</td>
<td>12 (34.3)</td>
<td>13 (28.9)</td>
</tr>
<tr>
<td>No</td>
<td>55 (68.8)</td>
<td>23 (65.7)</td>
<td>32 (71.1)</td>
</tr>
<tr>
<td><strong>Physical effects reported</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>9 (11.3)</td>
<td>6 (17.1)</td>
<td>3 (6.7)</td>
</tr>
<tr>
<td>No</td>
<td>71 (88.8)</td>
<td>29 (82.9)</td>
<td>42 (93.3)</td>
</tr>
<tr>
<td><strong>Suicide attempt reported</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>16 (20)</td>
<td>7 (20)</td>
<td>9 (20)</td>
</tr>
<tr>
<td>No</td>
<td>64 (80)</td>
<td>28 (80)</td>
<td>36 (80)</td>
</tr>
</tbody>
</table>
**Expectations of attending the group**

It was not possible to conduct a chi-square analysis on the 'expectations' variable due to the small numbers within some of the categories. Descriptive details are listed in Table 5, as well as examples to illustrate how responses were coded.

<table>
<thead>
<tr>
<th>Expectation</th>
<th>All N (%)</th>
<th>Drop N (%)</th>
<th>Comp. N (%)</th>
<th>Examples</th>
</tr>
</thead>
</table>
| Positive    | 45 (71.4) | 20 (76.9)  | 25 (67.6)   | "to be able to let go of it all, to heal"  
"to be able to put things in perspective, to feel less guilty"  
"to get rid of the cancer that living with these experiences feels like"  
"to hear others saying things that validate experiences and reactions, to talk to people that really understand" |
| Concerned    | 7 (11.1)  | 3 (11.5)   | 4 (10.8)    | "concerned about the emotional pain"  
"anxious about being in the group, meeting other people" |
| Mixed       | 11 (17.5) | 3 (11.5)   | 8 (21.6)    | "to talk about the issues, but ashamed of particular events-unsure of how will cope"  
"petrified but willing, expect talking to fellow survivors will help" |
Discussion
This study suggests that the profile of women who complete the survivors of sexual abuse group in this particular service are largely similar to those who dropout, although there are some important differences. It was found that dropouts did differ significantly from completers on the variable of 'identity of abuser', thus supporting part of the first hypothesis. This difference was also found by Fisher et al (1994). The second hypothesis regarding social support was not supported. However it may be that it is the quality of support that is important, and this may be something the service wishes to investigate further.

Interestingly there was a significant difference between completers and dropouts on the 'interpersonal effects reported' variable. As Sanderson's (1990) categorisation illustrates, this involves difficulties relating to others, and may also encompass difficulties with trust. A group situation initially may therefore prove too demanding for certain individuals. Certainly Saxe and Johnson (1999) found that interpersonal difficulties did not improve as much as intrapersonal symptomatology in their group treatment programme.

In terms of demographics and service-related factors a significant difference was found between the 2 groups on the 'age at assessment' variable. From the mean scores it was evident that completers were older than dropouts and this age difference was significant. However it is important to explore this further, and it may be that there are other factors that mediate or moderate this relationship. For example Goodman and Nowak-Scibelli, (1985) discovered that women who had received individual therapy prior to attending group therapy appeared to benefit more from the group treatment than those that had not. Thus it is possible that women who are older may have had more opportunity to be exposed to individual therapy than women who are younger, therefore individual therapy may be an important moderating variable which influences retention, and may prove useful for the service to consider the effects of this further.
Limitations of the study

As the study entailed a retrospective analysis of clinical notes it was restricted to the data that was collected at the time. This limited the nature of what could be sampled. It is not known for example to what extent ethnicity and culture may have been important, as this was not held within the data. However a wealth of other factors could have affected dropout, such as the practical limitations of transport and finances (Ruest, Thomlinson & Lattie, 1999).

Furthermore the changes in the assessment process, with the utilisation of a standard form from group 4 onwards, may have given rise to some of the missing data, as categorisation of variables included in the study was largely based upon the assessment form, and certain data e.g. 'expectations' may not have been collected as routine practice prior to this.

Implications for the service

The results obtained showed that there was a significant difference between the women completing the survivors group compared to women dropping out in terms of age at assessment, identity of the abuser and interpersonal effects reported. Further investigation into these issues is required. It may be that other factors such as utilising individual therapy prior to embarking on the group, or running a tailored group in order to focus on the specific issues for women who share these particular characteristics may prevent attrition. Other methods such as using a support worker who meets weekly with each group member have been used with some survivors groups (Watson, 1996).

It would seem from the profile of attendance following assessment, that a large number of women dropped out immediately following the assessment (n=20), or shortly after. This has implications for the individual concerned as well as the remaining group members and therapists involved. The individual who has dropped out may feel guilty, or a failure, and be reluctant to engage in future psychotherapy. The cohesiveness and commitment of the remaining group members may be affected and therapists involved may experience their own negative affect (Tweed & Salter, 2000). Aside from the practical limitations mentioned earlier, there could be many
reasons for this dropout, including an incorrect referral decision (Keen et al., 1996), or the trauma and pain of revealing information which was previously kept hidden (Frenken & Van Stolk, 1990; cited in Llewelyn, 1997). Some women may prefer individual therapy, which has been shown to be effective for women survivors (Price, Hilsenroth, Petretic-Jackson & Bonge, 2001). In order to reduce the rate of dropout some measures could be taken such as: providing more information to referrers about the group, perhaps in the form of a leaflet; sending the referrer a standard form to complete to gain greater information on the individual and why they feel a group would be of particular benefit; and systematically following up individuals who dropout at any stage following the assessment and invitation to join the group. The individual could also be given more information at the assessment interview regarding the benefits of group therapy, and their perceptions on this form of treatment compared to individual therapy could be explored.

It is recommended that the assessment form be altered. Other factors, such as previous exposure to individual therapy, whether this was found to be useful, and if not why this was the case, could be included on the form. The layout could be revised with the number of open-ended categories reduced, as the researcher found certain categories e.g. 'support' and 'relationships', 'nature of abuse' and 'circumstances of abuse' to duplicate information. Space could also be conserved by using more visual methods e.g. a geneogram for family and relationship history, and a visual timeline to pinpoint onset of abuse and duration, plus other significant life events.

As this study has given greater knowledge as to the profile of women completing the group it may also be useful for the service to gain a greater understanding of the groups' effectiveness. Standardised self-report measures could be used in the evaluation process, and other means could be employed, such as group feedback (Watson et al., 1996).
Conclusion

It would appear that this study has achieved its identified aims. It has provided a profile of the women who are assessed and then subsequently dropout or complete a survivors of sexual abuse therapy group and has thus improved the knowledge base for the adult mental health service concerned. It has also given many avenues for future investigation and evaluation.
References


Appendices

Appendix A: Survivors of Sexual Abuse Group Assessment Form
Appendix B: Codes used
Appendix C: Categorisation of qualitative data
Appendix D: Clinical Audit Protocol Form
Appendix E: Audit Declaration Form
Appendix F: Letter re feeding back to service
Appendix A: Survivors of Sexual Abuse Group Assessment Form
<table>
<thead>
<tr>
<th>SURVIVORS OF SEXUAL ABUSE GROUP ASSESSMENT FORM</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name:</td>
</tr>
<tr>
<td>DOB:</td>
</tr>
<tr>
<td>Address:</td>
</tr>
<tr>
<td>Assessment Date:</td>
</tr>
<tr>
<td>Occupation:</td>
</tr>
<tr>
<td>Telephone No:</td>
</tr>
<tr>
<td>Marital Status:</td>
</tr>
<tr>
<td>Name of Referrer:</td>
</tr>
<tr>
<td>Name of Kin/Primary Carer:</td>
</tr>
<tr>
<td>Telephone No:</td>
</tr>
<tr>
<td>Occupational Therapist:</td>
</tr>
<tr>
<td>Social Worker:</td>
</tr>
<tr>
<td>Occasional Service:</td>
</tr>
<tr>
<td>Others:</td>
</tr>
<tr>
<td>DED:</td>
</tr>
<tr>
<td>Date:</td>
</tr>
<tr>
<td>131</td>
</tr>
</tbody>
</table>
**MILY BACKGROUND:**

<table>
<thead>
<tr>
<th>ESENT CIRCUMSTANCES:</th>
</tr>
</thead>
<tbody>
<tr>
<td>WORK:</td>
</tr>
<tr>
<td>CHILDREN:</td>
</tr>
<tr>
<td>RELATIONSHIPS:</td>
</tr>
<tr>
<td>AVAILABLE SUPPORT:</td>
</tr>
<tr>
<td>NITY OF ABUSER:</td>
</tr>
<tr>
<td>NUMSTANCES:</td>
</tr>
<tr>
<td>NTIFIED EFFECTS/SYMPOTMS:</td>
</tr>
<tr>
<td>RUDE TO GROUP WORK/EXPECTATIONS:</td>
</tr>
</tbody>
</table>

**Service-Related Research Project**
Appendix B: Codes used
Codes used
The codes which were used are shown below in Table 6. The categories are largely derived from the survivors assessment form listed in Appendix A.

<table>
<thead>
<tr>
<th>Category</th>
<th>Code used</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name</td>
<td>numerical code entered – to ensure anonymity</td>
</tr>
<tr>
<td>DOB:</td>
<td>Assessment date-DOB=age at time of assessment entered</td>
</tr>
<tr>
<td>Location</td>
<td>1=next major town&gt;8 miles, 2=same town as group location, 3=other places</td>
</tr>
<tr>
<td>Occupation</td>
<td>Not used</td>
</tr>
<tr>
<td>Telephone</td>
<td>Not used</td>
</tr>
<tr>
<td>Marital Status</td>
<td>1=single, 2=married/co-habiting, 3=divorced/separated</td>
</tr>
<tr>
<td>Referrer</td>
<td>1=CPN, 2=Psychologist, 3=OT, 4=Psychiatrist, 5=other e.g. GP</td>
</tr>
<tr>
<td>GP</td>
<td>Not used</td>
</tr>
<tr>
<td>Next of kin</td>
<td>Not used</td>
</tr>
<tr>
<td>OT</td>
<td>Not used</td>
</tr>
<tr>
<td>Social Worker</td>
<td>Not used</td>
</tr>
<tr>
<td>CPN</td>
<td>Not used</td>
</tr>
<tr>
<td>Advocacy</td>
<td>Not used</td>
</tr>
<tr>
<td>Others</td>
<td>Not used</td>
</tr>
<tr>
<td>Medication</td>
<td>Split into 2 categories: anti-depressants e.g. citalopram, anti-psychotics e.g. thioridazine; l=yes, 2=no</td>
</tr>
<tr>
<td>Signed</td>
<td>Not used</td>
</tr>
<tr>
<td>Date</td>
<td>Date of group start-date of assessment=length of wait entered</td>
</tr>
<tr>
<td>Family background</td>
<td>Not used</td>
</tr>
<tr>
<td>Present circs</td>
<td>Not used</td>
</tr>
<tr>
<td>Work</td>
<td>1=yes, 2=no</td>
</tr>
<tr>
<td>Children</td>
<td>1=yes, 2=no</td>
</tr>
<tr>
<td>Relationships</td>
<td>Information supplemented support categories</td>
</tr>
<tr>
<td>Support</td>
<td>Split into 4 categories: support from partner, family, friend, other e.g. professional; 1=yes, 2=no</td>
</tr>
<tr>
<td>Nature of Abuse</td>
<td>Split into 3 categories: intercourse-l=yes, 2=no; touching-l=yes, 2=inc masturbation, 3=no; other abuse-l=photos taken, 2=oral sex, 3=bribes, 4=threats, 5=combination, 6=no</td>
</tr>
<tr>
<td>Identity of Abuser</td>
<td>Split into 2 categories: identity-l=father, 2=stepfather, 3=brother, 4=other male relation e.g. uncle, 5=male outside of family e.g. neighbour, 6=combination, 7=female (Recoded into 1= within family, 2=outside of family/combination*; number of abusers-l=one, 2=two, 3=several</td>
</tr>
<tr>
<td>Age</td>
<td>Split into 2 categories: age began-entered; duration-entered</td>
</tr>
<tr>
<td>Circumstances</td>
<td>Information generally duplicated nature of abuse category. Constructed</td>
</tr>
</tbody>
</table>
variable 'Disclosed at the time': 1=yes, 2=no

<table>
<thead>
<tr>
<th>Effects</th>
<th>Split into 6 categories according to Sanderson (1990, see Appendix C); emotional, interpersonal, sexual, behavioural, cognitive, physical; 1=yes, 2=no</th>
</tr>
</thead>
<tbody>
<tr>
<td>Expectations</td>
<td>1=positive statement, 2=concerned, 3=combination</td>
</tr>
</tbody>
</table>

*This variable was recoded to allow for appropriate statistical analysis i.e. chi-square.

In addition to the category headings listed on the form other categories were constructed based upon the data, and areas of interest to the service. These are listed in Table 7 below.

Table 7: Additional categories and codings used

<table>
<thead>
<tr>
<th>Disclosed at the time</th>
<th>1=yes, 2=no</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical abuse reported</td>
<td>1=yes, 2=no</td>
</tr>
<tr>
<td>Suicide attempt reported</td>
<td>1=yes, 2=no</td>
</tr>
<tr>
<td>Authorities notified</td>
<td>1=yes, but no action, 2=yes, and sentenced, 3=no</td>
</tr>
</tbody>
</table>
Appendix C: Categorisation of qualitative data
Categorisation of qualitative data

Effects of CSA
The long-term effects of abuse which were listed on the assessment form were categorised using Sanderson's (1990) classification as shown below.

*Emotional effects:* Depression, Low Self Esteem, Guilt, Anxiety, Obsessive/Compulsive, Anger

*Interpersonal effects:* Isolation/Alienation, General Social Relationships, Relationships with Men/Women/Parents, Effects on Parenting, Fear of Intimacy, Revictimisation

*Behavioural effects:* Self Destructive Behaviours, Self Mutilation, Suicide, Eating Disorders, Alcohol/Drug Abuse

*Cognitive effects:* Denial, Cognitive Distortions, Dissociation, Amnesia, Multiple Personality, Nightmares, Hallucinations

*Physical effects:* Psychosomatic pains, Sleep disturbances

*Sexual effects:* Impaired motivation/arousal/orgasm, Phobias/aversions, Sexual dissatisfaction, Vaginismus, Dyspareunia, Inability to separate sex from affection, Oversexualisation, Promiscuity, Prostitution

An example of the coding for the 'effects' variable is listed below:

*Response:* “Previous anorexia and bulimia aged 17 with recurring episodes over the years. Now very wary of men. Can’t trust them. Won’t be in a lift on her own with a man, feels vulnerable on her own. Dislikes herself a lot. Used to burn herself with an iron-needed to punish herself. Gets angry with herself. Experiences lack of sexual response to husband”.

*Codings:* Emotional: Yes Interpersonal: Yes Sexual: Yes Behavioural: Yes Cognitive: No Physical: No Suicide attempt: No
Nature and circumstances of abuse

An example of how this was coded is given below:

*Response:* "Intercourse from age 10. Previous inappropriate touching. Not violent but bribed her. Happened every time mother was out working. Never disclosed. Ended when x refused to be alone with him-fearful of what people would think".

*Codings:*
- Intercourse: Yes
- Touching: Yes
- Other abuse: Bribes
- Disclosed at time: No
Appendix D: Clinical Audit Protocol Form
Project Title: Retrospective Analysis of Survivors of Sexual Abuse Group

Reason for Choosing this Topic: Please state reason and indicate which Performance Assessment Framework (PAF) area the audit will provide evidence for.

- Health Improvement □
- Fair Access □
- Effective Delivery of appropriate health care ☑
- Efficiency ☑
- Patient/Carer Experience □

Objectives of the Audit:
To provide information as to the number and profile of women:
- Being assessed for the group
- Completing the group
- Dropping out of the group.

What Information Needs to be Collected in Order to Achieve the Objectives:
(Criteria)
information held on assessment form - eg
- demographic detailing age/marital status
- support available
- referral source
- abuse history

Sources of Data Collection:
Pre-group assessment form.

Professional Leading the Audit:
Clinical Governance Area: Adult Mental Health

Which other Staff/Professionals will be involved in the audit:
No other staff will be directly involved.

Who has been Contacted: Co-facilitators of the group in order to discuss aims/objectives of the audit.

<table>
<thead>
<tr>
<th>Name</th>
<th>Name</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| Name | Name | 140
Methodology:
- Include who collects information, when and how it will be collected (analysed)
- Methodology: collect Retrospective case note analysis – using assessment forms only.
- Analysis: On SPSS (using descriptive statistics, chi-squared and Independent T-test)

What is the selection criteria, for inclusion, in the audit:
- Time period: January 2002 – May 2002
- Sample size: Approximately 80
- Sample group: All women assessed for a Sexual Abuse group

Retrospective / Concurrent

What Possible Actions May be Taken at the End of the Audit:
- More specific criteria developed for group inclusion, change to assessment process

Is this Action Likely to Have a Cost Implication?
- No

Ethics:
- Have the ethical implications been discussed? Yes ☑ No □
- Are there any ethical implications? Yes ☑ No □
  - If yes, give details and what action needs to be taken:
    - Any identifying information is to be anonymised prior to analysis by the audit lead.

What support will be required from the Clinical Audit Department:
- None

To Whom will the Following be Available:
- Detailed Report:
  - University of Surrey
- Summary Evaluation: Clinical Governance Sub Committee, Clinical Audit Annual Report

What were the recommendations:

Re-audit date:
Re-audit findings:

All data collected during the audit will be treated as strictly confidential.
Appendix E: Audit Declaration 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.
Appendix F: Letter re feeding back to service
3 October 2002

Jo Boulter  
Department of Clinical Psychology  
University of Surrey  
GUILDFORD  
GU2 5XH

Dear Jo

Re: Survivors Group Research Study

Thank you for sending your study. Apologies about the delay in responding, but I had been on annual leave.

It has been very useful and I am arranging a time to discuss it further with Mandy, CPN and Teresa, OT.

Many thanks,

Maeve Crowley  
Consultant Clinical Psychologist
Major Research Project

Being healthy: a qualitative study exploring the understanding and experiences of adults with a learning disability

July 2004
Year 3
Abstract

This study explored how adults with a learning disability understood health and the behaviours they engaged in, in order to be healthy. It also explored their experiences about factors which may hinder them in this process. Semi-structured interviews were used to elicit the accounts of six women and six men with a learning disability, aged between 22 and 52 years. The interview transcripts were analysed according to the principles of interpretative phenomenological analysis (Smith & Osborn, 2003). Analysis revealed four superordinate themes: representations of health, staying healthy, improving health and barriers. Participants represented health in more than just uni-dimensional ways. Several actions were engaged in by participants in order to stay healthy, and the involvement of a range of individuals was identified as important to this state. In certain areas the knowledge base of participants was found to be underdeveloped. In terms of barriers to health, the choices participants made, as well as particular social influences played an important role in affecting engagement in health behaviours. The findings are considered in relation to the existing literature and methodological issues discussed. Finally clinical implications of the research are given and avenues for future research outlined.
Introduction

This research study aimed to explore how adults with a learning disability understand and experience health, and the behaviours they engage in to be healthy. The study was also interested in exploring their perspectives and experiences about factors which may have hindered them from engaging in these health behaviours.

Initially the key concepts of health and health behaviour will be defined and discussed. Attention will then be turned specifically to people with a learning disability, and evidence pertaining to their health status, reasons for unmet health needs and ways of improving health will be described. The inclusion of people with a learning disability in health-related research will be discussed before the rationale and research questions for the current study are presented.

**Health**

'Health' can be defined as "a state of complete physical, mental and social well being" (World Health Organisation; WHO, 1947) (p29). This definition offers a multidimensional perspective of health and gives emphasis to mental and social well being as well as the more traditional medical focus upon physical health (Ogden, 2000).

**Representations of health**

The way in which health has been conceptualised by individuals has been examined. Bauman (1961), for example, questioned a sample of 462 individuals comprising patients and medical students about what they considered "most people" meant when they reported to be in good health. Three categories of response were found: absence of symptoms; positive feeling states, and performance of normal activities. These categories could be regarded as coinciding fairly well with physical, mental and social well being detailed in the WHO definition. Indeed over 50% of the sample gave responses that fell into more than one category again indicating that multidimensional views of health were held. In more recent research Lau (1997) asked 156 young adults to describe 'What being healthy means to you'. Responses fell into several categories: 'physiological/physical' which incorporated being in a good condition,
having energy, and not tiring easily; 'psychological' which included feeling good mentally, feeling happy, and having a positive self-image; 'behavioural' which included ability to do normal activities, eating and sleeping properly; 'future consequences', such as living longer, and lastly 'the absence of' something, such as not getting sick, having no symptoms or disease. Lau (1997) found the physiological/physical category to feature most, with 75% of the sample giving a response which held this meaning. The study appeared to show according to Lau (1997) that health was not just the absence of illness and that most people held a positive definition of health, in that it is the presence of health that allowed them to do and feel certain things, as opposed to the absence of ill health.

What it means to be healthy, that is the representation of health, has been explored within other populations, for example Hall, Epstein and McNeil (1989) explored the beliefs of 590 older people aged 70 and above, whilst Hays and Stewart's (1990) sample comprised people who were suffering from a chronic illness. In both these populations 'health' could be considered to be more significant for these individuals, as it was not a 'given' and thus could not be taken for granted, however the results were similar to the studies discussed earlier, in that health was conceptualised as being multidimensional, and incorporated physical, psychological and social elements. Another population which is regarded as having considerable health needs is that of people with a learning disability, as discussed below, however little research has been conducted as to how health is represented within this population.

Health behaviour
Closely related to health is health behaviour. This can be defined as “any activity undertaken by an individual, regardless of actual or perceived health status, for the purpose of promoting, protecting or maintaining health, whether or not such behaviour is objectively effective towards that end” (WHO, 1986, p8). Gochman (1997) notes that behaviour used in this context referred to things individuals do or refrain from doing, which may not always be conscious or necessarily voluntary.
Models of health behaviour

Several models have been developed in order to explain and predict who is more likely to engage in health-related behaviour. The Health Belief model (Becker, 1974) for example viewed individuals as undertaking a form of cost/benefit analysis in their health-related behaviour. Specifically behaviour was felt to be the outcome of individuals’ perceptions of the severity of and their susceptibility to illness, the perceived benefits and costs of engaging in health-related behaviour and particular cues to action. This model has undergone various revisions and further components have been included which have been found to be important such as health motivation, and perceived control (Ogden, 2000). Other models have emphasised different aspects. For example the Theory of Planned Behaviour (Ajzen, 1988) identified behavioural intentions as the proximal determinant of behaviour. These behavioural intentions are the result of several other factors namely: attitudes towards a behaviour, which is composed of an evaluation and beliefs about the outcome of that behaviour; subjective norm, which is composed of the beliefs about others’ attitudes to the behaviour, that is the perception of social norms and social pressure, as well as the individual’s evaluation of their motivation to comply with others; and lastly perceived behavioural control, which is composed of a belief that the individual can perform a behaviour given various internal control factors such as skills, abilities and information, as well as external control factors such as opportunities and obstacles. This model has received much support in the literature in terms of its utility in predicting health behaviour in individuals (Armitage & Conner, 2000).

However there has been a burgeoning of models, with some such as the transtheoretical model of change (Prochaska & DiClemente, 1984) viewing health behaviour as encapsulating many discrete stages. Whilst it is not possible to discuss the various models in detail here, it may be that it is the components of these models rather than any particular model itself which is significant in understanding and predicting health behaviour in individuals. Indeed constructs such as attitudes, self-efficacy, norms, intentions, environmental constraints, skills and abilities have all been identified as important to health behaviour, and could even be integrated to form one major model (Armitage & Conner, 2000). However, models of health behaviour have been developed for use in the general population, and may not be applicable to
other populations, such as people with a learning disability, given the impact of their intellectual difficulties and their social and economic circumstances, for example, which may be more influential in governing health behaviour.

**People with a learning disability**

People who are considered as having a learning disability show significant impairments in intellectual as well as adaptive functioning prior to adulthood, that is, 18 years of age (British Psychological Society, 2001). Current prevalence rates suggest that approximately 1.4 million people have a learning disability with the United Kingdom, with most (1.2 million) having a mild or moderate learning disability (Department of Health; DoH, 2001).

The lives of many people with a learning disability have altered as a result of services adopting the principles of normalisation and social role valorization (Wolfensberger, 1983) operationalised in terms of O’Brien’s (1987) five ‘service accomplishments’. Changes in living arrangements, opportunities to engage in work and new leisure activities for example have given many adults with a learning disability more choices and increased independence (Jobling, 2001). However it has been queried whether such changes correlate with improvements in health status (Jobling, 2001), and whether this may indeed impact upon areas where health risks have been found to be lower than the general population, such as with alcohol and tobacco consumption (Turner & Hatton, 1998). The health status of people with a learning disability shall now be considered.

**Health status of people with a learning disability**

People with a learning disability are likely to have many health needs. Within this population sensory impairments of a visual and auditory nature are common, and are estimated as occurring in up to 60% of individuals who have a learning disability (Espie & Brown, 1998). Conditions such as epilepsy, psychiatric illness, and dental disease have been found to occur more frequently than in the general population (Kerr, Fraser & Felce, 1996). Furthermore heart disease (Turner & Moss, 1996), obesity, particularly in women with a learning disability (Turner & Hatton, 1998) and
musculoskeletal problems (Beange, McElduff & Baker, 1995) have also been found to be highly prevalent within this group.

Despite this array of health problems, there are some conditions which people with a learning disability are less likely than the general population to encounter. These include deaths from motor vehicle accidents given that few people with a learning disability are able to drive, and most cancers (Turner & Hatton, 1998).

Whilst there is reduced risk of some conditions, certain health problems are more prevalent within specific sub-groups of this population. For example people with Down’s syndrome are at increased risk of conditions such as Alzheimer’s disease; congenital heart disease; leukaemia; vision and hearing loss; thyroid disease; immunological deficiencies; respiratory disease and arthritis (Turner & Hatton, 1998).

Attention has also been turned towards lifestyle factors which may affect the health status of individuals with a learning disability. For example one study examined the lifestyle related risk factors for poor health, and found that individuals with milder forms of learning disability who lived in less restrictive environments were more likely to have a poor diet, smoke and suffer from obesity than individuals who had more severe forms of learning disability and lived in more restrictive settings (Robertson et al., 2000). Thus it is important to recognise that there is much heterogeneity within people who are classed as having a learning disability, not just in terms of health status, but also in individuals’ vastly different abilities and circumstances (Emerson, Hatton, Bromley & Caine, 1998).

Potential unmet health needs of people with a learning disability

Although the health needs of people with a learning disability may be considerable, many of these needs are not being met (Matthews & Hegarty, 1997). Various reasons have been cited to account for this. One reason which has been given considerable attention in the literature is communication. People with a learning disability are known to have difficulties in understanding and in communicating (Kerr et al., 1996). This is likely to affect their ability to recognise and report symptoms in order to gain access to appropriate health care, and may make them more at risk of misdiagnosis.
Major Research Project

and absent or inappropriate treatment (Beange, Lennox & Parmenter, 1999). Carers have been found to have similar problems in identifying the existence of health problems in individuals with a learning disability (Meehan, Moore & Barr, 1995). Furthermore, gaining access to health care may be dependent upon carers who may be reluctant to make demands upon GPs time, and so the reporting of symptoms may not occur until the condition has become much more evident and advanced (Beange & Bauman, 1990). Should a doctor-patient consultation take place this may also be confounded by the GPs level of expertise, which may not be particularly developed in conversing with people with a learning disability whose language ability may be poor (Kerr et al, 1996).

Another reason which has been cited is the existence of behavioural problems, which may be particularly acute in terms of individuals cooperating with novel procedures or examinations which they do not understand (Evenhuis et al., 2001). A further reason for unmet health needs is that of screening. There is evidence to suggest that there has been a lack of screening of particular health conditions for people with a learning disability who are based in institutions (e.g. McCulloch, Sludden, Mckeown & Kerr, 1996) as well as individuals who live in the community (e.g. Piachaud, Rohde & Pasupathy, 1998). Therefore health problems may not be initially detected in order for them to be treated.

Improving health in people with a learning disability

In view of the above, there have been moves to alter the health status of people with a learning disability. This has occurred at a national level with the publication of several Government documents aimed at improving the health of people with a learning disability, and increasing their access to health services. These include 'Health of the Nation: a strategy for people with learning disabilities' (DoH, 1995), 'Signposts for Success in commissioning and providing health services for people with learning disabilities' (DoH, 1998), and most recently 'Valuing People: a new strategy for learning disability for the 21st century' (DoH, 2001). 'Valuing People' however broadens its focus to incorporate many different aspects of an individual's life in addition to health, such as employment, housing and leisure, where improvements are sought. Several objectives are listed, with those most relevant to
improving the health of people with a learning disability being objectives 5 and 10, relating to good health, and workforce and planning respectively, shown in Table 1 below.

Table 1: Objectives

<table>
<thead>
<tr>
<th>Objective No.</th>
<th>Details of Objective</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>To enable people with learning disabilities to access a health service designed around their individual needs, with fast and convenient care delivered to a consistently high standard, and with additional support where necessary.</td>
</tr>
<tr>
<td>10</td>
<td>To ensure that social and health care staff working with people with learning disabilities are appropriately skilled, trained and qualified; and to promote a better understanding of the needs of people with learning disabilities amongst the wider workforce.</td>
</tr>
</tbody>
</table>

On a more local level many services have piloted initiatives aimed at improving the health of people with a learning disability. These have included the development of specific health measures such as a health assessment checklist (Matthews & Hegarty, 1997), and a health monitoring tool referred to as the health log (Curtice & Long, 2002), to assist with identifying and monitoring of any health problems. Further measures aimed at health surveillance include health screening clinics (Meehan et al., 1995), and health checks (Martin, Roy & Wells, 1997), which have been shown to be useful.

Additionally, enhancing understanding through educating carers (Fernando, Cresswell & Barakat, 2001), as well as GPs (Lennox & Kerr, 1997) has been suggested in the research literature as ways to improve the health of people with a learning disability. Jobling (2001) notes that better education in schools for children with learning disabilities on the topic of healthy lifestyles is one way in which change may occur. Indeed education and training programmes have been found to be beneficial for adults with a learning disability, for example individuals’ ability to communicate about illness and symptomatology improved following participation in a recent training programme (Dodd & Brunker, 1999).
Including people with learning disabilities in research

Until fairly recently much research has been conducted about people with a learning disability without directly including them within the research process. Many of the studies detailed above sought the opinions of other people, such as carers, on the issue of health in people with a learning disability. However such third-party information can be limiting and subject to various biases. Another way of improving health for this population may be to include them within research about themselves. There is increasing recognition of the value of this approach, which allows the views and experiences of individuals to be acquired first-hand, and enables information to emerge which may not be otherwise obtained (Chappell, 2000). Recently research has occurred which has examined the experiences and perspectives of people with a learning disability on a wide range of topics, including for example their understanding of illness (Butler, 2001), pain (Stone Pearn, 2002), and self-harm (Alexander & Clare, 2004). Limited research however has been conducted into people with a learning disabilities' own experiences of health, although some studies have recently occurred which examine certain behaviours related to health in adults with a learning disability. These encompass key areas such as eating, exercise, smoking and screening, and will briefly be discussed below.

The eating habits of 30 individuals with differing degrees of learning disability who lived in various types of accommodation such as family homes, staffed houses and independently was explored by Rodgers (1998). Rodgers found, after interviewing individuals and their carers, that the majority of participants did not plan what they were going to consume, did not participate in food shopping, had little involvement in cooking food, and had little knowledge relating to what constituted healthy or unhealthy food. Whilst the findings are interesting a limitation of the study is that many of the quotes listed are from carers, and it is not known the extent to which the conclusions drawn were based upon information obtained from the person with the learning disability. This latter point could also be applied to a study in which Messant, Cooke and Long (1998, 1999) explored the levels of physical activity of 24 adults with differing degrees of learning disability whilst evaluating a community based exercise intervention programme. Part of the outcome evaluation involved interviewing the participants and also the carers. Comments regarding the exercise
Some studies have sought to use questionnaires in obtaining information from people with a learning disability on aspects of their health. For example the prevalence of smoking and influences of this activity were researched in adults with a learning disability by Whitaker & Hughes (2003). Three day centres and a local college were sampled and out of 581 individuals only 11 identified themselves as smokers, giving a prevalence rate of 1.89%. Smokers were age and sex matched with their peers. A questionnaire was then provided to each smoker and matched non-smoker, and a separate questionnaire completed by their main carer. Smokers were found to be significantly more likely to live with someone that smoked than non-smokers. The majority of smokers attributed their onset of smoking to the influence of family and friends, and wished to stop smoking. Reasons for the non-uptake of this activity were also given by non-smokers. Whilst the results of this study are interesting the use of a questionnaire may have limited the amount of information that could be acquired, given that the reading and writing ability of many people with a learning disability may be compromised. This may have necessitated carer involvement which may have influenced some of the responses supplied. Another instance in which this method of data collection was used was by Davies & Duff (2001), who explored the use of breast cancer screening in older women with a learning disability living in community homes via postal questionnaires. Of the 59% response rate which produced 58 returned questionnaires, it was found that one-third had received invitations to attend mammography, and another third carried out regular breast examinations. Again given the questionnaire method used the extent to which carer involvement occurred in its completion is not known. Furthermore little information is offered regarding the views of those individuals who did carry out regular breast examinations.
Rationale for the current study

Much has been written about the ill health, and health needs, of people with a learning disability, however it would seem vital to readdress the balance by focusing upon 'health' in people with a learning disability given its importance and significance in achieving a good quality of life. Models which have been developed for the general population to make sense of and predict health behaviour, along with the constructs used, may not be applicable to people with a learning disability given the impact of their intellectual difficulties, and their social and economic circumstances. Furthermore more individuals with a learning disability may need to access healthcare as the median life expectancy of people with learning disabilities has increased to 66.2 years (Braddock, 1999). Therefore given this increased longevity and the considerable health needs of this population as discussed earlier, preventing ill health by maintaining good health seems the most desirable way forward. A proactive preventative approach to health as opposed to a reactive passive strategy could be argued to be an important quality of life factor and also be more time and cost effective, an important consideration in the current NHS climate.

Although the above studies have explored some aspects of health with people with a learning disability, little research has been conducted into how adults with a learning disability represent, define and conceptualise health. Little is known about their understanding of health or their personal beliefs about what they consider they do to be healthy, that is their health behaviour. Little is known about their experiences of healthy behaviour, or their perspectives upon what might prevent or hinder them from being healthy.

By directly obtaining accounts of healthy behaviours from adults with a learning disability and details of what stops them behaving in this way, greater information would be acquired about the type of concepts held, and about how people with a learning disability communicate their knowledge of health. This would provide information useful in the education of staff, and also have an impact upon health promotion work in highlighting the differences in communication styles and the variability of beliefs surrounding health behaviours which are likely to be present. It may also help to facilitate the 'good health' objective, which is one of ten objectives
listed in 'Valuing People' the government white paper for people with a learning disability (DoH, 2001).

Research questions

In light of what has been discussed there seems a need to address several questions on this issue. Consequently the first aim of this study is to explore how people with a learning disability understand and experience health, and so discover what they do to be healthy, that is their health behaviours. The second aim is to explore their experiences and perspectives about factors which may stop or hinder them from engaging in such health behaviours.
Method

Research Design

Qualitative research

Qualitative research is diverse in nature, encompassing a range of methodologies and associated epistemologies (Yardley, 2000). Despite these differences, what unites these approaches is a shared concern for meaning, and a keenness to focus on the 'quality and texture' of individual experiences about a particular phenomena (Willig, 2001). The intention is to understand a person's frame of reference, as opposed to producing generalisable statements following the testing of hypotheses (Turpin et al., 1997).

There is an increasing awareness of the value of qualitative research within clinical psychology, and it has been regarded as particularly useful when investigating new or under-developed areas (Turpin et al., 1997). Indeed the use of qualitative research has risen considerably within the last 5 years (Elliott, Fischer & Rennie, 1999), and certainly many studies have chosen to employ qualitative methods with people with a learning disability (e.g. Holland & Meddis, 1997; Smyly & Elsworth, 1997). However little research had been conducted in to how people with a learning disability understand and engage in healthy behaviours and what might prevent them from acting in more healthy ways. Consequently there was a need for the current study to be exploratory in nature, which befitted the use of a qualitative approach.

The particular qualitative approach which was adopted was that of Interpretative Phenomenological Analysis, which is detailed below.

Interpretative Phenomenological Analysis (IPA)

Interpretative Phenomenological Analysis (IPA) is a qualitative approach which emerged within the arena of health psychology (Smith, 1996). It is designed to explore in detail the individual's views and experiences of the area under investigation. The approach is phenomenological in nature, as it is concerned with capturing how a person perceives and understands events. However Smith, Jarman and Osborn (1999) acknowledge that "access [to the individuals personal world] depends on, and is complicated by, the researcher's own conceptions and indeed these
are required in order to make sense of that other personal world through a process of interpretative activity” (p218). This approach accepts that the researchers own beliefs and experiences will be influential in shaping the outcome of the analytic process. Therefore what emerges is seen as being jointly constructed between the individual and researcher (Osborn & Smith, 1998). IPA has been used previously with individuals with a learning disability in unpublished (e.g. Butler, 2001) as well as published research (e.g. Alexander & Clare, 2004).

As this research is interested in exploring how people with a learning disability understand and experience being healthy, IPA seemed particularly appropriate given its emphasis on capturing, and making sense of individual experiences and meanings. Furthermore as the researcher envisaged adopting an active role in supporting participants to reflect and communicate their experiences, IPA recognises the role of the researcher and their influence in the process and outcome of research.

**Participants**

**Selection of participants**

Certain inclusion criteria were applied in order to ensure that the sample constituted adults who had a recognised learning disability, and who were able to communicate verbally. Therefore in order to be eligible for inclusion into the study all participants needed to meet the following inclusion criteria:

a) be aged between 18-65 years
b) use spoken language to communicate
c) have previously attended a school for children with learning difficulties (moderate or severe)
d) be recognised as having a learning disability/access services for people with a learning disability

In addition certain individuals were considered as not being suitable for the research as they may have had difficulties understanding and responding to questions in a meaningful way. Therefore the following exclusion criteria were applied in order to exclude individuals who were considered to be not appropriate for the research:
e) has an autistic spectrum disorder
f) has dementia/suspected dementia

Participant characteristics
The way in which the participants were recruited is described in the procedure section. This process resulted in a sample consisting of 12 participants, six women and six men aged between 22 and 52 years (mean age = 32.7 years, s.d. = 9.7 years). All participants were of white British ethnic origin and used English as their first language. Details relating to participant characteristics were obtained through completion of a brief background information form by the keyworker (see Appendix A). Six participants lived with their family, four resided in a group home, and two lived independently in the community. In terms of the types of activities participants engaged in during the week, five attended a day centre, three attended college, eight had some form of part-time paid employment and three individuals worked in a voluntary capacity. With regard to health problems, eight participants had problems with their eyesight, which was managed for seven participants through wearing glasses, and three through regular check-ups. Three participants had problems with their teeth, and so had regular check-ups. Two participants had epilepsy and were on medication to manage this. One participant was on medication for depression. One participant had cerebral palsy, one had asthma and another had problems related to their knee. Table 2 gives details of participants’ scores on the language assessments, which are described in the section below.

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5 Some participants engaged in more than one of the activities listed.
6 Further details relating to the language assessments are given in Appendix B to help situate the sample.
Table 2: Participants language assessment scores

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<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Gender</th>
<th>Renfrew Raw Scores</th>
<th>BPVS Raw Scores (Max =168)</th>
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<td></td>
<td></td>
<td>Information (Max = 40)</td>
<td>Grammar (Max = 36)</td>
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<tr>
<td>Nigel</td>
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<td>Male</td>
<td>34</td>
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</tr>
</tbody>
</table>

Instruments

Language Assessments

Two language assessments were conducted, which provided details regarding the expressive and receptive language abilities of the participants within this study. This information, in conjunction with the demographic details and the health problems given on the background information form, are supplied in order to 'situate the sample' (Elliott et al., 1999), which is a procedure considered good practice in qualitative research. This information may also help orientate the reader to the range of people to whom the findings may be relevant.


This test provides a measure of expressive language ability. Individuals are shown 10 picture cards depicting everyday scenes (e.g. a child posting a letter, a dog tied to a post), and are asked a question relating to each picture. Responses are evaluated in terms of the information supplied and the grammatical structures used. This measure was originally devised for children aged 3 to 8 years, and has not yet been standardised for use with other populations, although it has been used previously in

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7 Pseudonyms are used throughout to protect the confidentiality of the participants, and those who are referred to in the context of the research.
research with adults with a learning disability (e.g. Butler, 2001; Stone Pearn, 2002). The raw scores are offered as a means of describing participants' individual abilities.


This test provides a measure of receptive language ability. Individuals are shown a series of 4 pictures and are asked to identify the picture which best corresponds to a given word. This measure was originally developed for children aged 3-15 years. It has been used in research with adults who have a learning disability (e.g. Dodd & Brunker, 1999). It is used here as a way of illustrating participants' receptive language abilities, for which the raw scores are presented.

Interview schedule

The use of semi-structured interviews was regarded as the most appropriate method of data collection. This approach tends to generate richer data than structured interviews as it affords the interviewer greater flexibility to explore issues which arise in greater depth (Smith, 1995). Within this study it would facilitate further exploration of individuals' responses, and also allow the researcher to work flexibly with differences in individuals' communication abilities or styles, which given that the sample involved people with a learning disability, was considered to be a possibility.

Questions that were incorporated into the interview schedule (see Appendix C) were predominantly centred around three areas; firstly with identifying and recognising health/health behaviours in self and others, which can be seen through questions such as 'How healthy are you?'; 'How do you know when someone is healthy?'; secondly relating to their experiences of the causes and consequences of health/health behaviours, seen through questions such as 'What people are important in keeping you healthy, 'What do you like/not like about X?'; and lastly concerning factors that inhibited health behaviours through questions such as 'What stops you being healthy?'. In devising the interview schedule attention was also paid to the various models of health behaviour that exist. As discussed in the introduction there are certain key concepts such as self-efficacy or control, attitudes and norms, that have been regarded as useful in helping understand and predict who may engage in health-
related behaviour. Whilst these models may not be appropriate to people with a learning disability, as discussed earlier, some of the concepts were used to guide the types of questions asked, for example 'What can you do to make yourself more healthy?' was influenced by the concept of self-efficacy.

Furthermore in designing the interview schedule consideration was given to the literature on interviewing people with a learning disability in view of some of the known difficulties people have in understanding and responding to certain wording, such as double negatives, and certain types of question (Prosser & Bromley, 1998). Indeed the problem of acquiescence in this population, particularly to closed questions, is well documented (Sigelman, Budd, Spaniel & Schoenrock, 1981). Given the nature of the research and its aims in seeking to explore participants' understanding and experiences, open-ended as opposed to closed questions tended to be used in the interview schedule as this type of questioning is recognised as the most appropriate format for ascertaining the participants' perspective (Finlay & Lyons, 2001). A technique called 'funnelling' was also employed (Smith, 1995) in which a more general non-focused question was asked initially, such as 'What healthy things do you do?', before a more defined and specific question was given, such as 'How do you keep your teeth healthy?'. Furthermore the use of alternative words and phrases was incorporated into the interview schedule, as is recommended in the literature to enhance understanding (Finlay & Lyons, 2001). For example, on the initial questions within the interview schedule the word 'well' could be used instead of 'healthy' for individuals who did not appear to fully understand this term. In addition to consulting the literature, discussions were held with research and field supervisors who were Psychologists experienced in working with this population.

Piloting

The language assessments and interview schedule were piloted on the first two participants. In order to help the participants become more familiar and at ease with the researcher, the language assessments were administered prior to the semi-structured interview. One factor that emerged from piloting was that the administration of the language assessments was shorter than originally envisaged. Although the language assessments and interview were intended to be conducted
separately over two sessions, this seemed less appropriate given the shorter duration, and reduced likelihood of participant fatigue. This was altered for the main study to one session although two sessions occurred when this was preferred by participants.

A further feature that emerged from piloting was that most of the questions asked on the interview schedule were found to produce appropriate responses from the participants. However, a few questions generated a poor response such as ‘What do you like about being healthy?’ In such cases the wording of the question was altered for the main study and so, for example, this question was rephrased to ‘What’s good about being healthy?’. Aside from these factors, the procedure for the main study remained the same as for the pilot study, therefore data collected from the participants in the pilot was retained for inclusion.

Procedure
Ethical approval
Ethical approval was sought, and obtained, from two ethics committees (see Appendix D): the Local Research Ethics Committee in which locality the study was carried out and the University of Surrey Advisory Committee on Ethics.

Recruitment of participants
The researcher disseminated details of the research to services through which it was envisaged the sample would be drawn. This comprised a local service which helps people with a learning disability find part-time employment, and the Community Learning Disability Team. Copies of the participant Information Sheet were given to managers within these services, which they were asked to show to individuals who met the inclusion criteria for the study. Details such as the name and contact number of individuals who appeared interested in participating in the research, or who wanted to meet the researcher prior to deciding whether to take part, were passed to the researcher. The researcher then made arrangements to meet with the individuals at a time and location that was convenient to them. None of the individuals were seen at their place of work, as this was considered to be too intrusive. The location typically consisted of the individual’s home or a local day centre which they attended. This
necessitated further dissemination of the research to other individuals such as the potential participant’s family or their keyworker at the day centre.

This method of recruitment resulted in 15 individuals being invited to speak with the researcher in order that the study be fully explained, and individuals given the opportunity to decide whether to participate in the research. One person did not wish to take part, resulting in 14 individuals who were willing to be involved and who signed the consent form. Difficulties occurred with the tape recorder for one participant, whilst another had considerable speech and language problems resulting in their account being largely inaudible on tape, consequently the sample comprised 12 participants.

Acquiring informed consent
Several aspects of the procedure were designed to facilitate informed consent. Documentation given to participants, that is the information sheet (see Appendix E) and consent form (see Appendix F), was assessed for readability by applying the Flesch reading ease scale, and any complex sentence structures were subsequently altered to heighten the readability of the material. Individuals were approached about the research by a person familiar to them, and provided with a copy of the information sheet, which clearly stated they could discuss the research with other individuals and take their time in deciding whether to take part. At the initial meeting between the researcher and the potential participant the study was described again, the information sheet was presented verbally, and a further copy given to the potential participant should their original have gone astray. Potential participants were encouraged to ask questions about the research, after which their understanding of the research was gauged using questions specifically designed for this purpose with people with a learning disability (Arscott, Dagnan & Kroese, 1998), and clarifications made where necessary. Individuals who wished to take part in the research were then asked to sign the consent form, which was also presented verbally. As stated on the consent form the participant’s GP was then contacted and informed that they had given their agreement to participate in the research (see Appendix G).
Administration of the language assessments and interview schedule
All 12 participants completed the Renfrew Action Picture Test (4th edition) (Renfrew, 1997) and the BPVS-II (Dunn et al., 1997). These assessments were conducted on a one to one basis with each participant, except one individual who wanted their key worker present. The administration of these measures took approximately 25 minutes. Similarly, aside from one participant who wished for her key worker to be present, the researcher met individually with all the participants for the interview. The interviews were conducted at the participant's home or at the day centre they attended. The interview schedule was flexibly applied, in that the wording of questions was adapted where necessary to assist understanding, and questions were incorporated into the flow of conversation between the participant and researcher. The interviews were between 25 and 40 minutes in duration, and all were audio-taped. Following the interview the researcher once again checked with each participant that they were happy for the tape recorded conversation to be included in the research. All participants reiterated that their interview could be used. Participants were thanked for their inclusion in the research and reminded that they would receive information about the findings, as detailed in the information sheet, following completion of the research. The audio-tapes of the interviews were transcribed verbatim before being erased. Participants were not paid for their involvement in the research.

Data analysis
The interview transcripts were analysed using the idiographic case study approach detailed in Smith et al. (1999). This process began with a thorough examination of one interview transcript in which interesting or significant details, such as initial associations or summaries, were noted in the left margin. Next emerging themes, that is, key words which encompassed the individual's account were listed in the right margin. Connections between the emerging themes were then sought, which involved clustering themes together in order to produce a table of themes. Within the table of themes, superordinate as well as subordinate themes were listed alongside supporting evidence from the text. This procedure was repeated for the remaining transcripts, and the list of themes was added to or amended accordingly as new themes emerged or existing themes altered through the course of the analysis. Some themes were discarded when it was considered they became less meaningful. Following the
consolidation of the individual's table of themes a master list of themes for the group was created.

A sample size of approximately 10 participants is generally regarded as appropriate when using the idiographic case study approach (Smith et al., 1999). Given that individuals with a learning disability may not provide accounts which are as detailed as the general population, a greater number was sought, and 12 participants obtained.

**Evaluating qualitative research**

Qualitative methods are being increasingly employed (Turpin et al., 1997). Consequently greater consideration has been given towards the most appropriate means through which to evaluate the quality of qualitative research (Yardley, 2000). Although qualitative approaches are diverse in nature they share a common aim towards understanding, and acknowledge a more active role of the researcher in the research process. Willig (2001) asserts that criteria such as reliability, validity, representativeness, generalisability and objectivity, through which quantitative research is evaluated, can not be meaningfully applied to qualitative research due to its differing emphasis and aims. In view of this other forms of evaluative criteria have been proposed (e.g. Henwood & Pidgeon, 1992; Elliott et al., 1999). Elliott et al., (1999) recently provided a set of guidelines applicable to both quantitative and qualitative research, as well as further guidelines which were specifically related to qualitative research. Willig (2001) notes that two of these criteria are particularly pertinent to IPA, that of grounding interpretations in the data, and issues of reflexivity. Elliot et al.'s (1999) guidelines for qualitative research are listed below with details of how this research meets each of these criteria, with particular emphasis being placed upon 'owning one's perspective' and 'grounding in examples'.

1. **Owning one's perspective**

The researcher had previous experience of working with people with a learning disability, and developed her interest in this area through involvement in a health promotion day for people with learning disabilities whilst undertaking a clinical placement. The researcher considered the research literature to be somewhat skewed to areas such as 'challenging behaviour', with there being a relative neglect of
research orientated towards health for this population, even though their health needs are considerable. The researcher also felt that people with a learning disability tended to be marginalised within research with opinions, values and attitudes being sought from carers, staff and GPs, notably anybody it seemed but the person with the learning disability. The researcher therefore felt it was important to enable the voice of the person with the learning disability to be heard through the research, and hoped to demonstrate that individuals had relevant and valuable points to make. Further issues of reflexivity are given in the discussion section.

2. Situating the sample
Information relating to the characteristics of the participants, such as their age, gender and ethnicity, as well as social circumstances such as their living arrangements, are given to assist the reader in judging to whom the findings of the research might be relevant.

3. Grounding in examples
Examples of the data in the form of direct quotations from the interview transcripts are utilised throughout the analysis section. The examples enable the reader to appraise the fit between the data and the researcher’s comprehension of it, and also provide a means through which possible alternative understandings or meanings can be conceived.

4. Providing credibility checks
In checking for the credibility of the themes identified by the researcher, the views and opinions of 5 research peers and 3 research psychologists at an IPA group were sought. At the IPA group one transcript was reviewed in depth, and the themes which had been identified by the researcher discussed. The thoughts and ideas arising from the IPA group were subsequently incorporated into the analysis. The themes which emerged were also discussed separately with a research psychologist.

5. Coherence
The study is presented in a coherent and integrated way, whilst preserving nuances in the data which are noted and discussed.
6. Accomplishing general vs. specific research tasks
The aim of this study was to explore the experiences of a small group of adults with a learning disability in terms of how they conceptualise being healthy, and their understanding of factors which might prevent them from being healthy. The findings are not intended to be representative of this population as a whole, or indeed generalisable to other adults with a learning disability. By providing demographic and contextual details, the reader may decide the extent to which these findings might be similar to other individuals or groups.

7. Resonating with readers
The researcher has endeavoured to accurately reflect the participants' ideas and experiences about being healthy, and present this in as clear and insightful way as possible. In so doing it is intended that the reader's appreciation and understanding of this area will have been both broadened and enhanced.
Results

Four superordinate themes emerged through the analysis, and these as well as the subordinate themes, are shown in Table 3. Given the considerations of space available, it was not possible to include all of the identified themes. The theme of improving health will not be presented here as it is not as directly related to the research questions. This theme encompassed overcoming previous ill health as well as future changes and relates to participants' experiences of occasions in the past when they were not so healthy, and the means through which they regained their sense of health, as well as participants' beliefs relating to changes they could employ in order to become healthier. Instead the researcher focused on the themes which provided a coherent narrative about the understanding and experiences that participants had about health, staying healthy and the barriers to health which they encountered.

Table 3: Superordinate and subordinate themes

<table>
<thead>
<tr>
<th>Superordinate theme</th>
<th>Subordinate theme</th>
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<tbody>
<tr>
<td>Representations of health</td>
<td>As a construct</td>
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<tr>
<td></td>
<td>In terms of self</td>
</tr>
<tr>
<td></td>
<td>In terms of others</td>
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<tr>
<td>Staying healthy</td>
<td>Actions of self</td>
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<td></td>
<td>Involvement of others</td>
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<tr>
<td>Improving health</td>
<td>Overcoming previous ill health</td>
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<td></td>
<td>Future changes</td>
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<tr>
<td>Barriers</td>
<td>Individual choice</td>
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<tr>
<td></td>
<td>Social influences</td>
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</tbody>
</table>

Representations of health

All twelve participants described how they understood health. This was in terms of their own health, the health of others, as well as health as a construct in a more general sense. Participants' representations seemed to alter in view of this, and included health represented as the absence of illness, as well as in behavioural, physical and psychological terms, which are similar to the categorisations used by Lau (1997) as discussed in the introduction. This theme is concerned with participants' understanding of health, as opposed to what they do to be healthy which is encompassed within the superordinate theme of 'staying healthy'. Behavioural
representations of health tended to dominate the participants’ accounts of health when this was discussed as a construct in an abstract sense, whilst more varied representations arose when they spoke about their own or others’ health. However health conceptualised as the absence of illness seemed notably lacking in participants’ representations of their own health, although this featured within the other two subordinate themes.

-As a construct
The majority of the participants gave behavioural representations of health, when they were asked to explain what being healthy means. Grant, Claire, Katie, Sophie, Lily, Laura, Jessica and Derek all identified health in this way. Food of a certain type, typically fruit and vegetables, tended to be used to illustrate this, for example Derek explained “means eating the right fruit and veg, the right diet”, similarly Jessica spoke about “eating properly and things, make sure you have eat fruit and things”. Andy and Mark combined behavioural as well as physical elements in how they represented health, whilst Nigel represented health in solely physical terms by referring to aspects such as strength and fitness, as shown below.

I: What does being healthy mean?
P: Being fit
I: Being fit?
P: Yeah, strong

Jason represented the construct of health very differently from the other participants. He described being healthy as not being ill, therefore his representation of health seemed to encompass health as the absence of illness. He also spoke about being looked after, which suggested an awareness of social influences upon health. Finally Jason made reference to being well on the inside, which could be interpreted in two ways, either as signifying healthy internal organs, or possibly alluding to being in good health psychologically.
P: “What does it mean? Um ... It means when you very healthy, and you're healthy, you're not ill and anything like that, you're not ill, you're looked after well, or you're well in the inside and that, you see”.

-In terms of self

Whilst a few of the participants seemed uncertain of their own health status, Claire for example said that she was “healthy I suppose. I haven't got a clue”, several of the participants were able to reflect upon their own health with more awareness. Health tended to be represented in either physical, behavioural and psychological terms, or a combination of these.

For example Derek provided a physical conceptualisation of his own health by noting that he was “quite fit and healthy”. Lily and Andy also represented their health physically. For example when asked how healthy he was Andy made reference to his body, specifically his weight, and showed awareness of how he got to this state through consuming more food than he needed at meal times. He explained:

P: I'm too heavy. It's here, round here (points to stomach)
I: Round your belly?
P: Yeah. I eat too much dinner.

Grant represented his own health in what seemed to be both physical and psychological terms. Grant made reference to internal organs in his body as healthy, whilst his gesture and accompanying reference to the inside of his head showed some awareness of psychological health. Grant seemed to acknowledge that some parts of his body could be healthy, whilst at the same time others may not be. He also seemed aware that health was not an absolute invariant state, but something which changed over time.

I: So how healthy would you say you are then?
P: Bit of both.
I: Bit of both, yeah. So tell me about the bit that's healthy then, and tell me about the bit that is not so healthy.
P: Healthy, my heart is healthy, my stomach is healthy. In here, that's not (points to head).
I: In here, in your head?
P: My head, sometimes I'm tired.
I: You're tired?
P: Sometimes I'm not, but sometimes I'm tired.
I: Mmm.
P: And the rest of it's fine.

Grant's talk of tiredness seemed to be a synonym for low mood, as he went on to explain that it was the weekend when he was not tired, given the social activity that occurred, as he described "at weekends, Saturday nights, we order a curry or watch TV or videos". Nigel and Mark also gave psychological representations of their own health, which seemed more positive than Grant's, for example when Mark was asked about his own health he commented "I'm alright actually", and went on to say "feel good, and all that lot, that's it really". When asked about how healthy she was Jessica identified that she was "not too bad" and later added that "I have things to do, don't I", suggesting she represented her own health behaviourally as she was able to engage in everyday activities.

-In terms of others
Some participants, such as Laura, Andy, and Jason talked about the presence of ill health in family members when asked about how they knew others were healthy, whilst other participants represented the health of others in terms of an absence of illness. Jessica, in the example below, talked about how she knew her dad was healthy by describing him as free from colds and coughs. These are visible symptoms of a common illness, and indeed visibility seemed to be important to participants in their representations of health, as several of the participants referred to visible, that is external signs of health throughout this superordinate theme. Internal and therefore invisible signs of health were less common, although occasionally featured, such as with Grant's reference to internal organs within the previous subordinate theme.
As mentioned above Jessica represented the health of her father in terms of the absence of illness. She identified that she knew he was healthy when coughs and colds were not present.

I: How do you know when other people are healthy, like your Dad? How can you tell when he is healthy?
P: He doesn’t get a cold and things, doesn’t sneeze and things, he’s not coughing over me

Jessica also spoke about the health of her work colleagues in a similar way “Most people are not too bad at work, most of them are quite healthy… as they are not coughing and sneezing”. Absence of illness was also described by Lily in response to being asked about how she could tell others were healthy “When they’re nothing wrong with them. There’s nothing wrong with my sister”.

Health in others was also represented by participants in psychological terms, through reference to mood for example. This is evidenced in Lily’s account, as in addition to perceiving health as the absence of illness Lily explained that people looked “different, happier”, when they were healthy, whereas when unhealthy they appeared “Not happy, and all like depressed, kind of”. Psychological as well as physical representations of health were also described by Nigel when referring to others health. He emphasised that others looked a certain way such as healthy and strong, again suggesting that visibility was important.

I: How can you tell when someone is healthy?
P: They look healthy don’t they?
I: They look healthy?
P: They’re happy.
I: Right, mmm
P: They look strong.

Derek also gave a physical explanation for how he knew others were healthy “Weight they are, and all that lot, how big they are, and fitness they are”. In addition to
perceiving health as the absence of illness in others Jessica also gave a physical explanation “They’ve got the right colour and things”, which she explained was not pale, and again within Jessica’s and Derek’s accounts the element of visibility is apparent.

**Staying healthy**

All participants described actions which they undertook in order to stay healthy. Similarly all participants identified that other people were involved in this process, and described a range of individuals as well as types of involvement.

**Actions of self**

In order to stay healthy participants identified a number of actions which they carried out. These actions could be viewed as constituting different types of health behaviours, such as engaging in exercise, eating healthy foods, and not smoking. The rationale behind these actions seemed predominantly linked to averting unwanted consequences, although there was awareness of some benefits these actions bring. However in some instances participants did not appear to know the rationale for the actions they had identified.

Nearly all of the participants identified undertaking some type of exercise in order to stay healthy. Many of the participants including Nigel, Grant, Claire, Katie, Lily, Mark and Jessica identified walking as the exercise they engaged in. For example when asked about what healthy things she did Jessica explained:

\[
\text{P: I do a lot of walking, and things as well... I walk in to work every day.}
\]

\[
\text{I: What is it about walking that helps to keep you healthy?}
\]

\[
\text{P: Give you exercise.}
\]

Mark also identified “I do mostly walking... good exercise, I need it as well”, and explained why this was the case. Certain benefits of exercise seemed to feature in his account, notably weight loss. This is an external and consequently visible indicator of health, and is also present in Katie’s account which follows. Mark associated being
fat with negative social comments. For Mark a further benefit was social acceptance, as he considered that weight loss would facilitate approval from others.

P: Sometimes you like lose weight, and all that lot.
I: Right. Is that a good thing then?
P: To lose weight, yeah.
I: How come that’s good?
P: If you’re like, sort of fat and that, some people take the mick, and lose weight that would be good
I: Mmm, how much weight would be good to lose?
P: I don’t know really. Anything would do.

He went on to say “If you lose a lot of weight then people will like you”.

Katie similarly identified certain activities as healthy and explained why this was the case. As with Mark weight loss was also pertinent to Katie’s account.

I: What other healthy things do you do?
P: Sometimes I go swimming. Sometimes I go like walking.
I: Oh, right. So, how do those things keep you healthy?
P: Makes you lose weight.

Participants also identified other means of exercise they engaged in. Derek spoke about playing football to keep his fitness up, whilst Jessica and Lily mentioned undertaking household chores. For example in response to being asked about what healthy things she did Lily described more typical forms of exercise as well as those that involved household tasks:

P: I go on a walk. I do a bit of shopping, and I go horse riding.... I do a bit of hoovering up at home, and wash up.
I: Tell me how these things are healthy.
P: Exercising.
Some participants such as Nigel, Grant and Claire seemed unsure about the rationale behind the activity they had identified. For example when asked about how walking kept him healthy Grant replied "It just does". Similarly Claire who had identified walking as an activity that she did to keep healthy did not know why this might be so, as shown below:

I: So what's good about walking?
P: Exercise
I: How does it keep you healthy?
P: Don't know.

Sophie described going to the gym, and identified some physical effects of this. However she did not seem to fully understand what was helpful about this for her health:

P: I go to the gym on Tuesdays
I: What do you do at the gym?
P: Bike, walking machine, rowing machine
I: How does that help you keep healthy?
P: Busy... get your heart pumping
I: Oh, it gets your heart pumping. What's good about that?
P: I don't know

However, Sophie was one of the few participants who made any spontaneous reference to their heart when talking about health. Indeed some participants seemed not to be aware of this organ at all as evidenced by Andy below, which has certain clinical implications discussed later.

I: What about your heart. How do you keep your heart healthy?
P: What's your heart?

A further action which several participants such as Grant, Laura and Jessica spoke about in order to stay healthy was that of not smoking. Indeed some participants such
as Sophie, Mark, Jason and Derek referred to this spontaneously without direct questioning. Smoking was always construed negatively by participants, who seemed to hold strong attitudes and beliefs about this activity. Many participants also demonstrated an awareness of the effects of this activity upon health, and indeed it is the only behaviour which several of the participants linked with death and disease. The influence of family and friends is also evident in participants’ accounts, and this overlaps with the ‘involvement of others’ theme, although it is presented here as it constitutes an action which participants chose not to perform, in order to stay healthy.

Mark identified himself as always being a non-smoker, and demonstrated a negative attitude towards smoking. He suggested that he had an insight into this activity through his family, work and college life. Furthermore, he assigned smoking as incurring many consequences, namely cancer and the curtailment of life and alluded to familial shame in telling others about this activity:

\[P: \text{I don't smoke. I can't stand it, I've never done it in my life, but I know what it's like because my brother smokes. It took him about 2 months to tell mum, and you can get cancer as well....Used to do a job in [place], pick all the rubbish up, all the cigarettes and that, and I quit the job because of all the cigarettes and that. I couldn't hack it. I felt sick as well. When I was at college lots of people ask me to try it, but I say 'No thanks, I want to live longer'.}\]

Similar to Mark, Grant identified a family connection with this behaviour, and held a strong belief about the consequences of engaging in this activity:

\[P: \text{My family smokes, my sister. I don't want to.}\]
\[I: \text{How come you don't want to?}\]
\[P: \text{If you smoke too much it will kill you. And that's it, it's bad.}\]

Jason talked about his mother and uncle smoking, and how he used to smoke but gave up, as did Derek. Jason seemed to be aware of the effects, particularly on his lungs,
and talked about this very descriptively, emphasising how dirty and unpleasant this activity was, and how this acted as a reminder to him of the effects:

P: *Smoke can kill you, it goes down to your lungs.*
I: What does it do to your lungs?
P: *Black, filthy... I've smoked cigarettes and cigars in the past. The whole lot is disgusting, because its smoke. You make your lungs black and filthy and horrible. It's nasty, makes it nasty, yeah, horrible. It's a horrible feeling, thinking about it you see.*

The lungs were a specific bodily organ which other participants, besides Jason, referred to as being affected by smoking. Laura described the effects of smoking on the lungs and also made reference to how she came to know about this through watching an advertisement on television.

P: *Your lungs go all black. And that advert you see on the telly with all that fatty stuff coming out. I wouldn't like that in my lungs.*

Indeed the lungs were the predominant bodily organ which participants made reference to, which was solely within the context of smoking. Whilst Mark identified this as causing cancer as detailed above, both Sophie and Jessica labelled the type of cancer that smoking was likely to cause, for example Sophie explained: "*Bad for your lungs... gives you lung cancer*".

Most of the participants described performing certain actions in order to keep their teeth healthy. As well as visiting the dentist which is discussed further in the subordinate theme of 'involvement of others' Nigel, Grant, Claire, Katie, Andy, Laura, Mark, Jessica, Jason and Derek described cleaning their teeth regularly, and identified the consequences of not undertaking this action. For example in response to being asked about how she kept her teeth healthy Laura described that she cleaned them in the morning and at night, and identified that if she did not their appearance may change in colour, and bacteria as well as fillings may result, as she explained:
P: *I keep cleaning them.*

I: Right, how often do you clean them?

P: *Morning and night.*

I: And how does that keep them healthy?

P: *If I didn’t they’d get yellow and bacteria, and fillings. That’s about it.*

Jason spoke about using “blue mouth wash” to keep his teeth healthy, and not eating sweets, “*But I don’t eat sweets a lot because that makes them unhealthy*”, as “Sugary sweets make your teeth fall out, eventually, not straight away but eventually they will do”. Mark had also talked about eating sweets and chocolates, and explained the action he had taken, that of purchasing a type of chewing gum, in an attempt to prevent having a filing or tooth extraction.

P: [after eating too many sweets] *Your teeth go bad, and the next thing you know you’ve got to have a filling or you’ve got to have your tooth taken out. I want to try and get away with it next time. That’s what I want to try and do. There’s special chewing gum to clean your teeth as well.*

I: Special chewing gum?

P: *I got that at work. I asked them if they had any.*

In terms of further actions which the participants performed, all of the participants made reference to diet, and identified consuming certain foods which they regarded as good for their health. However in some instances the responses possibly indicated an underdeveloped knowledge base. For example Grant had identified that it was important to “*eat healthy food ...and, umm, don’t eat the wrong food*”, although his subsequent response was slightly unusual:

I: Yeah, so what sorts of foods are healthy?

P: *Sometimes biscuits, some biscuits*

I: What sorts of biscuits?

P: *Er, like Rich Tea*
The majority of participants however tended to identify foods such as fruit and vegetables as healthy. For example Mark identified fruit as a food which was good for his health. However he seemed to view this in a different way from other types of food, given the prefix of 'special' that he used when discussing it. For example he described having “special food, like fruit ....and drink special stuff like water, I drink it every day”.

Like some other participants Mark seemed to have difficulty explaining what made the food he had identified healthy. When asked about how fruit helped to keep him healthy his response was centred around the physical attributes of the fruit, in that it was soft, as opposed to reference to the presence of vitamins or the absence of fat for example as shown below:

P: *I like bananas, that's my favourite fruit.*
I: Yeah, that's your favourite. How do they keep you healthy?
P: *Taste good, like all the other fruit and keep you healthy and that.*
I: What have they got in them that might keep you healthy?
P: *They are soft and that, like the other lot. That's it really.*

Some participants however did offer an explanation as to why the food they had identified could be considered healthy. For example Andy described eating particular foods and not others in order to stay healthy. He described certain fruits in a positive manner as energy giving, whilst other foodstuffs, namely crisps, were connoted negatively, due to the presence of salt which he linked with causing ill health, as he explained:

P: *Apples I eat, grapes. They are good for you aren't they?*
I: They are good for you. How are they good for you?
P: *What's the word? Gives you energy. I don't eat crisps.*
I: You don't eat crisps?
P: *I don't buy any.*
I: You don't buy any?
P: *No. They are bad for you. Too much salt, urghh.*
I: What does the salt do?
P: Make you ill.

Nigel also identified fruit as a form of food which was conducive to his health, as well as vegetables as they were energy giving, which is similar to the response provided by Andy.

I: What about, you said also Nigel about eating the right food keeps you healthy. What food is the right food?
P: Fruit is good for you, isn't it?
I: Yeah.
P: Vegetables
I: Yeah, what's good about them?
P: I think they give you energy.
I: Yeah. What fruit and vegetables do you eat?
P: Grapes, and carrots and beans and peas

However only a few participants, such as Claire and Lily spoke about the presence of vitamins in the foods they had identified to account for why they were healthy. An example of this is provided by Lily, and is encompassed within the 'involvement of others' theme which follows as her account also overlaps significantly with that theme. Here Lily identified that there is iron in cabbage which is good for her bones and body. Thus healthy food was connoted as such by participants due to it being energy giving and containing certain vitamins or minerals. None of the participants identified the importance of eating at least 5 portions of fruit and vegetables a day, a message which is currently fairly prevalent in society, in order to ward off particular health problems.

In conjunction with diet some participants such as Sophie and Jason described other actions that they performed which indicated that they were largely in control of and responsible for this area of their health. This relates to self-efficacy which is a concept found to be important in influencing health behaviour, and also features within other themes, such as 'involvement of others'. Within this theme Sophie for
example talked about doing her own food shopping, and when asked about who made her food she replied "I do". This degree of independence and control was also pertinent to Jason’s account as he explained "I get my weeks shopping... I decide everything really, y'know. I cook my own dinner, I do my own washing, do my own ironing, do my own this, do my own that". Other participants were even more explicit about identifying themselves as being responsible for their own health as when asked about who helps them be healthy Laura explained "Well, it's up to me really", whilst Katie identified "I can help myself", and Jessica described "My dad sometimes, but I can cope anyway", thereby acknowledging the role of others in her health. It is the involvement of others to which attention shall now be turned.

Involvement of others
Participants identified the involvement of other individuals in keeping them healthy. These ranged from family and friends to their keyworker as well as dentists and doctors. Involvement took many different forms and included the provision of advice and encouragement, rule-setting and warnings, as well as actual monitoring of the participant themselves.

Most of the participants, including Nigel, Grant, Claire, Andy, Lily, Jessica and Jason, talked about the involvement of their family in helping them stay healthy. The giving of advice was one way in which this occurred. For example Lily identified certain food as healthy, namely cabbage as it contained iron and vitamins, although she acknowledged that she was not totally certain about this statement. She identified that this information had been acquired through the advice given to her by certain family members. As Lily explained:

P: Cabbage has got irons in, good for your bones and your body. I think so, I'm not sure..., my sisters and my Mum and Dad used to say that. Vitamins in cabbage are good for you

Jessica, who lived independently in the community, described the involvement of her father as important in helping her stay healthy, and described this involvement in terms of him giving her advice about purchasing certain food and drink. As well as
the provision of advice her father seemed to be involved in a monitoring capacity ensuring that she had complied with his requests. Jessica also described negative consequences as ensuing if she ignored such advice.

I: Okay, what people would you say are important in helping keep you healthy?

P: Sometimes my Dad keeps an eye on me, ... My dad gives me advice on what things to buy. I'm not too bad.

I: Oh right, so your dad gives you advice about what to buy. What sorts of things does he tell you?

P: He says, buy bananas and orange juice, sort of thing he says to me, not too bad is it?

I: So will you take notice of what he says?

P: I have to, yes. Because I'm in trouble if I don't. (laughs)

I: (laughs). You're in trouble if you don't? What will he do?

P: He'll say 'What have you got these for?' He'll shoot me! (laughs).

Jason identified his mother as important in keeping him healthy. Initially it appeared that Jason was attributing sole responsibility for his health to his mother as he described that she looked after him and kept him healthy. However later on in his account he acknowledged a greater role for himself in maintaining his own health, and spoke about the choices he had, which indicated that he was aware of being in control of his health to some degree. This coincides with the concept of self-efficacy as mentioned in the previous theme. Jason described ill health as a consequence, should he choose to ignore his mother's advice.

P: Well, my Mum looks after me, she keeps me healthy.

I: What does she do to help keep you healthy?

P: ... my Mum says to keep me healthy 'When you go out, don't talk to any strangers'. That keeps me healthy. Another thing that keeps me healthy is, [she says] don't drink alcohol too much, because I'm on pills, I'm on tablets. If I drink about five in a night I'd be ill, so that's bad for you. I'd be sick, I'd be ill. So yeah, she's keeping me healthy in that way.
I: So you listen to what your Mum says?
P: Yeah, I do, I do. I don't have to but I mean, it's my choice, but I'd be stupid if I didn't listen to her. I do listen to her, because I know, at the end of the day, it's not her who's going to be ill, it's me who's going to be ill, not her. ...I listen to Mum when she want me healthy, because its no good drinking alcohol. It makes you sick, makes you ill, makes you bad.

Andy had also identified his mum as someone who helped him stay healthy. However in the account below it is apparent that he did not necessarily follow her advice. Like Jason, Andy appeared to be making certain choices arising from others involvement.

P: She says go for a swim. I say I don't want to go for a swim, I'll play squash.
I: Oh, you play squash?
P: Yeah, that's good exercise. That's good. That's good for you. I don't mind doing that.

Andy similarly identified his keyworker as somebody that helped him stay healthy. He had already talked about walking as a form of exercise that he engaged in, and spoke about how his keyworker encouraged him in safely undertaking this activity:

P: She helps me
I: She helps you?
P: Says 'Come on, go for a walk'
I: So she says go for a walk.
P: Around here, not on the road
I: Not on the road?
P: No 'cause you could get run over, you can get run over

Jason had also identified his keyworker as helping him stay healthy. He described the advice she gave him, which was similar to that which he received from his mother,
described earlier, although this seemed to encompass a specific warning about ill health following the consumption of a certain amount of alcohol, as he explained:

P: Tina, the manager of the houses, she says the same thing, 'Don't drink more than 3 or 4 or you'll be ill the next day'

Jason also identified the involvement of his friend in keeping him healthy. Whilst other friends appeared to exert a negative influence on his alcohol consumption discussed further in the theme of 'social influences', Jason identifies one particular friend who was aware that he was on medication and so would not purchase additional alcohol for him:

P: I've got a friend down [place] near my mum. He's normally goes to the pub ... but he knows I'm on tablets, so he wouldn't buy me more drinks than what I should do

When asked about other people who were helpful in keeping them healthy Nigel identified "the opticians, they make sure your eyes are alright". This professional group was similarly identified by Lily and Jessica, and their involvement discussed. Several participants including Nigel, Katie, Andy, Laura, Mark and Jessica also spoke about seeing the dentist in order to keep their teeth healthy. Some of the participants seemed particularly aware of the advice they had received, concerning omitting certain foodstuffs from their diet, as Andy explained "She says 'No sweets, no chocolate, leave chocolate alone". Mark also spoke about the dentist's involvement in telling him not to drink Coca Cola anymore, which seemed to constitute more than the provision of advice but the setting of certain rules around his behaviour as he acknowledged that Coca Cola was 'not allowed'. He explained:

P: It's got sugar in it. I got told by a dentist I'm not allowed to drink none of that stuff no more

Katie also described using a mouth wash "the wash-up stuff" which helped her stay healthy, and when asked about why this was she identified the dentist's involvement,
as well as what she was trying to prevent: "the dentist, 'cause you can get like a kind of mouth disease".

Most of the participants including Nigel, Katie, Sophie, Andy, Lily, Laura, Jessica, Jason and Derek identified their doctor as someone who was important to their health. However the doctors' involvement seemed to be centred around the provision of medication, and in some instances advice. This advice seemed to be dietary in nature, as for example Derek identified that they "tell you what to eat and what not to eat", whilst Katie identified that "they tell me not to eat fatty food, or things like that, because it's not good for your heart". This latter quote is interesting as it suggests that the doctors' involvement had a preventative function to it, although this does not seem to be acknowledged by the participants themselves. Participants made little reference to the preventative element of healthcare through practices such as check-ups or screening, which may have been indicative of a lack of knowledge in this area. The following responses regarding obtaining the doctors' involvement were typical. Katie said she would see the doctor "if I got a bit of a problem", Lily commented "If I'm not well I go and see a doctor, a doctor makes me feel better", whilst Jessica described that she needed to go:

P: When I'm not very well, sort of thing. There's a reason why for it. I don't need to come if there's no reason for it, don't go to doctors then as it's a waste of time if there's no reason

Similar accounts were obtained from Andy and Laura. Thus participants made little association between doctors and preventative healthcare, suggesting underdeveloped knowledge in this area.

Barriers

It was evident through participants' responses that there existed certain barriers which impeded them in being healthy. Some of these barriers related to the choices they

8 As participants' experiences related to the doctors involvement are primarily concerned with overcoming illness, these are encapsulated within the theme of 'overcoming previous ill health', which is not presented here.
made; whilst others seemed to be as a result of social influences. Whilst aspects relating to the participants' knowledge base may constitute a barrier to them making informed choices about health, participants rarely defined this themselves, therefore it would not be accurate to incorporate that within this theme.

**Individual choice**

Several participants adopted behaviours which seemed at odds with healthy behaviours. This appeared to be as a result of the decisions they made. In many instances such decisions appeared to be choices made actively by the participants in order to obtain something which was regarded as desirable, or avoid something which was considered unpleasant. For a few participants their decisions not to engage in healthy behaviours seemed as a consequence of little interest in undertaking that activity, suggesting an absence of motivational factors.

Grant identified his fondness for chocolate as something which impeded him in being healthy, and also described the way in which he actively enlisted others into acquiring this for him.

I: What things stop you being healthy?

P: Chocolate

I: Chocolate? You like chocolate? What do you have?

P: I like most of them with 2 chocolates, like a Twirl and Time Out.

I: Yeah.

P: My sister drives a car, and when she goes to the shops to get a newspaper and cigarettes sometimes I ask her and she'll get me a chocolate bar. And she gets me something like a Time Out. That's the best.

This keenness for confectionary was echoed by others such as Katie, Jessica and Nigel. For example when asked about the things he did which were not so healthy Nigel replied "Let's see. Some things I eat are not that healthy, sweets and that".

Jessica also identified that it was the perishable nature of certain fruit, as well as financial considerations, which influenced her purchasing decisions, as she described:
P: I like bananas, but the trouble with them is they go off. You've got to watch, haven't you?
I: How often would you have those then?
P: When I can afford them.

She later went on to say “I haven't had any fruit today. I haven't bought much this week. I couldn't afford it”.

The theme of individual choice seemed to emerge particularly in conjunction when the subject of alcohol was discussed by several of the male participants, including Mark, Nigel, Jason and Andy. For example Mark spoke about getting drunk, its effects on himself and how this state improved his snooker playing. Mark's justification for this behaviour when asked about how healthy this was suggests the element of choice involved, whilst his reference to orange juice may suggest that societal norms as well as social influences may also be affecting his behaviour.

P: ...I am funny when I am drunk. I had lots of drink on Saturday night as well. Playing snooker all night, that's when I'm good, playing snooker when I'm drunk.
I: So when you have a drink how healthy is that?
P: Not that healthy, but if you want a drink you got to have it. You can't go to the pub all night and have an orange juice...

Some participants seemed to choose to stop engaging in certain health-related behaviours on the basis of an unpleasant experience. For example Jason identified a need to wear glasses in certain circumstances such as for reading, writing and watching television although in practice he rarely wore them, as he explained:

P: Writing I don't do much anyway. TV I supposed to wear my glasses, but I don't, and I watch TV quite a bit. Reading, I don't read much anyway so I don't wear my glasses for reading
When asked about why he did not wear them for watching television he acknowledged that he did not like them near his eyes, and he had had an unpleasant early experience of wearing glasses. As he explained:

P: *It’s the thought of wearing them... They get in my eyes you see. I had them when I was 5 years old. I had a little squint in my eye, 20 years ago, I wore glasses 20 years ago and it was horrible*

A further choice which Jason seemed to have made related to exercise in the form of sport. Jason spoke of having "stopped doing the sports", and described an experience of having seizures when participating in this activity in the past. It seemed that non participation served a protective function for him in terms of preventing the occurrence of further seizures.

P: *I don’t like sports.*
I: What don’t you like about sports?
P: .... *I don’t like football, running around, tennis and squash. I don’t like any of that rubbish, ‘cause I remember when I was at school I remember I had a fit.*
I: That put you off then?
P: *Put me off sports, yeah.*
I: How often do you have fits now Jason?
P: *Now, not very often, but then it was very often. You see at the time I was doing sports, but now I say not very often.*

Grant also described a past experience which influenced his present day health behaviour. He identified dog walking as an activity which he did to assist his health, and described an incident which occurred in conjunction with this. Grant did not seem to have a great deal of control over his dog’s behaviour, which was consequently influential in his attitude toward further dog walking.

I: How do you look after your body? You mentioned walking. Is there anything else you do to look after it?
P: I used to take the dog for a walk.
I: Oh yeah.
P: I did it quite a while ago, quite a long time ago now, quite a long time ago. When I took the dog for a walk it was like, we went up the field, and were playing on the swings. There were lots of cars there, and people getting in their cars. I told the dog to stay with me, but she kept on pulling her lead, and ... the boy came up to the dog, and the dog started barking loudly to the boy. She kept on just going really fast and I couldn't hold her. She's a bit naughty sometimes, ... so I'm not particularly keen on walking dogs.

A few participants such as Nigel and Laura seemed to choose not to engage in healthy behaviours such as exercise, on account of little motivation for this activity. For example Laura identified that she did not engage in exercise as she "Just can't be bothered".

**Social influences**
The power which other people exerted appeared to be very influential for several participants in terms of their engagement in healthy behaviours. The opinions of others, either family or friends, seemed to carry much weight in effecting the participants uptake of behaviours that aided their health. This can also be seen within the 'involvement of others' theme which illustrates how others helped to produce and promote healthy behaviours, however within the theme of 'social influences' others had a constricting effect, and inhibited the participants' engagement in certain health behaviours.

Social influences appeared to be significant for many participants. For example Mark identified that he was "supposed to wear glasses", although it seemed that outside of the group home he did not, given the negative reaction he anticipated, or received, from others. Mark did not want to draw attention to himself by wearing glasses, which seemed to represent to him a sign of further disability, which he considered would magnify others perceptions of him in this context. However he later acknowledged the effects of wearing glasses, in terms of how he would feel if people made fun of him, as well as the effect on his eyesight. As Mark explained:
P: Some people take the mick out of you. I hear it lots of times, that's why I don't wear them at work you see.
I: Because of what other people might say.
P: Yeah, most people wear them at work, but I don't wear them 'cause people might say 'Look at him he's got everything'. I heard it lots of times.
I: If they said that then...[interrupted]
P: It would be a bit annoying what they said, but at least my eyes would be safe then....It's alright wear glasses here [in the group home], because no-one don't take the mick, but if you go like out, they might.

Similarly Nigel also identified that he had needed to wear glasses, however this was something he no longer did. He described that neither he, nor his mother thought this was necessary: "I didn't think I needed to. My mum didn't think I needed to".

Social influences were also important in terms of alcohol consumption. For example Jason talked about the contrast between his friends and his mother related to alcohol. Her influence has been previously discussed in the 'involvement of others' theme. It seemed that different individuals exerted contrasting influences over Jason depending on the context, with his friends being influential in encouraging him to consume more alcohol, as Jason explained:

P: My friends, well they're not like my Mum. They're friends in the pub with me, you know right. That's when my Mum worries about me a lot. They probably make me drink more than what I should be, you know

Whilst Jason acknowledged that he had certain limits for the amount of alcohol he consumed he identified that there were certain occasions in which he found it difficult to adhere to this given the social influences around him, as he went on to say:

P: I know I'm on tablets, ... I know every time I go down there, my limit is 3, but when I do go down there I am persuaded to drink more, at my niece's birthday or at Christmas time. Last Christmas I was persuaded to drink more...
It is acknowledged that for Mark, Nigel, and Jason, their experiences seem to overlap with the subordinate theme of 'individual choice', however the social influences appear to be particularly pronounced and influential in modifying the participants' health behaviour, and are therefore presented within this theme.

Social influences were also relevant to Grant's account, although it was the absence of individuals which was pertinent here, and meant that he no longer had the opportunity to go out running, as he explained:

P: *Used to go running, not any more*
I: How come you stopped running?
P: *Because my friends have grown up now and they do other things*
I: Oh right
P: *I'm always, sometimes at home, have been at home.*

A further social influence affecting the occurrence of health behaviour seemed to be the control other people had over the participants. In response to being asked about ways she could become healthier, Sophie, who lived in a group home, identified that she would like to go out independently, however was not permitted to do so⁹.

I: What do you think you could do Sophie to make yourself more healthy?
P: *Go out more.*
I: Go out more, like where?
P: *Anywhere. I'm not allowed to go out on my own.*

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⁹ Although this overlaps with the theme of 'future changes' it is presented here given its relevance to this theme.
Major Research Project

Discussion

The themes which emerged from participants' understanding and experiences of health and the behaviours they engaged in, in order to be healthy, as well as their beliefs about what prevented them from acting in this way, will be summarised and discussed in relation to the current knowledge base. Methodological issues will then be explored, and areas of strength as well as limitations of the research discussed. Lastly, clinical implications of the research, as well as possible areas for future research will be considered.

Summary of themes

One of the themes to emerge from analysis of the transcripts, was representations of health. Participants understood and represented health in behavioural, physical or psychological terms, or as the absence of illness. Indeed the way in which health was represented seemed to differ for some participants according to whether health was being represented as a construct in general terms, in terms of themselves or with reference to other people.

Another superordinate theme which emerged from participants' accounts was that of staying healthy. Participants identified many actions that they engaged in that contributed to staying healthy. These actions were performed by participants in order to avert unwanted consequences. However on some occasions the benefits of these actions was identified, though on others the rationale for the action was not known. Whilst some participants located responsibility and control of these actions within themselves, for many it was the involvement of others which was instrumental in the occurrence of these. Different forms of involvement were found to be acquired from a range of individuals.

The superordinate theme of barriers emerged through analysis of participants' views and beliefs about what may have served to impede them in being healthy. The choices which some participants made seemed to hinder their engagement in certain health behaviours. These decisions seemed to be based upon a motivation to obtain something desirable, or avoid something unpleasant, which held greater significance
than engagement in the healthy behaviour itself. In addition social influences were found to play a critical role in influencing the engagement in healthy behaviours for several participants.

**Comparing the findings with other research**

*Representations of health*

In the current study whilst a few participants provided unitary representations of health, which tended to be in behavioural terms, most represented health in multiple ways, in physical, behavioural, or psychological terms, or as the absence of illness. Therefore health appeared to hold for participants not one meaning but several. Indeed this is a finding which has been borne out in research with adults in the general population, as for example Lau (1997) found, as well as with other populations e.g. older people (Hall, et al., 1989), and those suffering from a chronic illness (Hays & Stewart, 1990).

However in the current study, the way in which health was represented by participants seemed to differ in certain ways according to whether health was being represented as a construct in general terms, or with regard to themselves or others. For example health as the absence of illness never featured in participants' representations of their own health, although this was frequently mentioned when participants referred to the health of others they knew such as family members. However whether such differences feature in other research is not clear, for example Blaxter (1990) sought a description from 9000 individuals about someone they considered to be healthy and then posed the following questions 'What makes you call them healthy?', 'What is it like when you are healthy?'. As such Blaxter (1990) appeared to ask questions relating to the health of others as well as to the individual, or even possibly relating to health as a construct should 'you' be interpreted in the abstract sense. Qualitative analysis on a sub-sample revealed broad responses, including health as: the absence of illness; having energy and vitality; being physically fit and able to function effectively and having social relationships with others.
Staying healthy

Participants described performing certain actions, which could be regarded as health behaviours in order to stay healthy. For example, many described engaging in exercise, which encompassed activities such as playing football, swimming, and going to the gym. This contrasts with the findings of Neumayer and Bleasdale (1996), who found that individuals with a learning disability rarely mentioned participating in active recreational activities. However, whilst a few of the female participants identified household chores such as hoovering as exercise, many of the participants identified walking, which seemed to constitute the predominant form of exercise.

Within the current study, whilst differing forms of exercise were identified, the benefits tended to be associated with weight loss, and little else. Participants rarely described how they felt psychologically after engaging in exercise, or how this activity might reduce the risk of certain conditions, such as stroke, cancer, or heart disease. Interestingly, the heart was rarely mentioned within this context, aside from Sophie, who did identify that exercise got her heart pumping, however, she did not seem to be aware of why this was beneficial. The clinical implications of this will be discussed.

Another action which participants discussed was that of eating certain foods which they deemed to be healthy. In terms of diet, many participants seemed aware of what constituted healthy foods, which contrasts with Rodgers' (1998) findings of individuals having little knowledge about which foods were in fact healthy. The reasons for these dissimilar findings could include differences in the levels of learning disability of the participants, as well as greater levels of health promotion having occurred since this study was conducted for example. Within the current study, however, few of the participants were able to describe why the foods which they had identified as healthy were regarded in this way. The clinical implications of this are discussed later. Some participants also acknowledged a degree of responsibility and control over their own health in this context, for example, Jason and Sophie both discussed how they purchased and prepared their own food. This contrasts with the work of Rodgers (1998) who found that carers were largely in control of planning individuals' diets and purchasing food. Whilst it is acknowledged that this may have been the case for some participants, particularly those that lived in family homes,
others seemed in control of what they bought and consumed. One reason for these differences in results is possibly due to the characteristics of the sample, such as the living situation and the degree of independence this afforded. Furthermore as the majority of participants engaged in some form of paid employment, this may have given them a greater degree of economic independence, and impacted upon their sense of self-efficacy in this context.

A further action which many of the participants identified was that of not smoking. Participants connoted this behaviour very negatively and described the consequences in terms of death and disease. This is similar to the findings of Whitaker & Hughes (2003), who examined the prevalence and influences on smoking in people with a learning disability and found that non-smokers cited the negative effect on health as the main reason for abstaining from smoking. In the current study participants described being influenced by their family and friends, some of whom did smoke, although one participant, Laura referred to an advertisement she had seen on television. This is an area which may merit further investigation as it has been questioned whether material which has been designed for the general population is accessible to individuals with a learning disability (Espie & Brown, 1998).

Participants discussed the involvement of others in helping them be healthy, and whilst the range of individuals identified varied, none of the participants made any direct or even indirect reference to having a health facilitator, which is specified in 'Valuing People' (DoH, 2001) as occurring by spring 2003. In addition little awareness was shown with regard to the preventative element of healthcare, as none of the participants described going to see their doctor for a 'check up', only if a problem was present, which again may hold particular clinical implications. Furthermore whilst much research has been concentrated on obtaining the views and perspectives of individuals who do not have a learning disability about those who do, little exists on the converse through which these findings can be discussed.

Within these findings constructs inherent within the various models of health behaviour, which are important in understanding and accounting for health behaviour, can be found. Attitudes, which is one construct, are prevalent throughout and
particularly when participants described benefits related to the action they were discussing such as not smoking. Another construct, that of self-efficacy or control can be seen when some participants talked about their diet and who was responsible for their health. Therefore within this particular group of people with a learning disability some constructs utilised in models of health behaviour were present.

**Barriers**

Barriers were identified which seemed to hinder participants up-take of certain health behaviours. Social influences appeared to be particularly powerful barrier to being healthy, especially for some young males in the study, who seemed to demonstrate a strong need to fit in and be socially accepted by others who may not have a learning disability. Similarly the control significant others had, such as family members and carers in influencing participants' behaviour seemed considerable. This latter point has implications for self-efficacy, as if carers fail to allow individuals the opportunity of some control and independence over their own health, dependence will be reinforced and this will restrict the individual in developing a greater sense of self-efficacy, which is known to be important in influencing the occurrence of healthy behaviours.

Several participants appeared to be making conscious choices about engaging in various actions which seemed to be in opposition to behaviours that could be regarded as healthy. These choices seemed to be influenced by their motivation to gain something desirable, or avoid something undesirable, which was more appealing than the health behaviour itself. In some respects this can be understood through a model of health behaviour, specifically aspects of the health belief model that has now been revised (Ogden, 2000), in which health motivation, as well as a weighing up of the cost and benefits of engaging in a particular health behaviour are considered to be influential in accounting for the occurrence of a health behaviour. In terms of the present study certainly previous negative experiences seemed to carry a great deal of significance for participants in affecting their engagement in healthy behaviours. For example, Grant was put off walking the dog after it barked ferociously at others, causing offence and humiliation, whilst Jason stopped participating in sports through his perception of this as causation for his seizures.
However previous research found that different barriers existed to health behaviours such as engaging in exercise. These included limited opportunities for community leisure, and restrictions on transport and staff (Messant et al., 1999). Similarly using focus groups with people with a learning disability, lack of transport and carer support was identified as the principle reasons impacting upon choice of leisure activity in a more recent study (Beart, Hawkins, Stenfert Kroese, Smithson & Tolosa, 2001). However in the current study these factors did not emerge. The reasons for this could be many, for example it is possible that carer support was not lacking for participants, as many identified the involvement of others in terms of helping them stay healthy, or it may have been that participants were not aware of transport restrictions, given perhaps they may have been more independent, and hence did not conceive of such factors as an issue. The methodological issues in conjunction with the strengths and limitations of this study will now be focused on, and emphasis given to the role of communication with this client group, which may in itself have acted as a ‘barrier’ to the research process.

Methodological issues

The strengths and limitations of the research

Research design

As little research had been conducted in this area with people who have a learning disability the research was exploratory in nature. In such circumstances, a qualitative research design is considered to be the most appropriate methodology (Turpin et al., 1997). Through the use of IPA, which incorporated semi-structured interviews as its data collection tool, participants’ understanding and experiences were explored in a flexible manner. This produced considerable breadth and depth of information which is considered a strength of the research. Such richness of data may not have occurred through the use of more quantitative methods such as standard questionnaires with this population, given the rigidity of the approach, as well as other considerations for example individuals possible difficulties with reading and writing.

Participants

The recommended number of participants when using IPA has been cited as 10 (Smith et al., 1999), however this method could be used appropriately with as few as
6 participants (Smith & Osborn, 2003). However as it was considered that the accounts of people with a learning disability may be less detailed, more participants were sought in the current study and 12 were obtained.

*Instruments*

The language assessments gave information relating to the expressive and receptive communication abilities of the participants and thus helped situate the sample. Furthermore as the language assessments occurred prior to the interview this provided time and space for the participants to become more at ease and familiar with the researcher, and may have helped reduce any initial anxieties the participants had.

The use of a semi-structured interview allowed participants to define and emphasise aspects of health which were pertinent to them, and enabled different avenues to be explored and language to be adapted where necessary to meet the needs of the individual participant.

The interview schedule held a discreet number of questions. Whilst it is recognised that more standard questions could have been included, it was felt that fewer questions enabled a fuller exploration of individuals' particular experiences and understanding through asking related follow up questions. Furthermore as participants were given the opportunity to define what they understood by health, and behaviours associated with this state, a wide range of ideas and beliefs were generated which is considered a strength of the research. Had a particular type of health behaviour, such as exercise, been defined by the researcher as the phenomenon under investigation and prescribed to participants, responses may have been more limited. In allowing participants to define their understanding of health, and health behaviours, they were able to draw upon their own experiences which in turn allowed them to engage in more meaningful discussion. It also may have given them more control over what they chose to discuss or not talk about. Related to this latter point is the fact that none of the participants brought up the issue of sexual health. Whilst the researcher could have asked about this area directly she chose not to for the following reasons. Firstly given the range of health behaviours that were being identified the researcher considered it important to explore these areas, without increasing the
breadth of the study further. Secondly she acknowledged that this may have proved a sensitive area for some participants, and given the time available for interview participants may have not felt comfortable discussing this subject with the researcher. This is an area for future research.

A further strength in relation to the interview schedule is that the questions within it were orientated towards the present. The researcher was aware that some people with a learning disability may have difficulties with retrospective questions given the demands this places upon memory. Aside from one question which asked about past experience generally the questions had a 'here and now' focus, which sought to overcome this potential difficulty.

However there were difficulties in acquiring particular types of information in the interview. A primary focus of the research was that of health-related behaviours, and indeed many of the experiences which participants described related to what they, or others did, that is their behaviour. Whilst some participants were able to spontaneously give information regarding their thoughts or feelings about their experiences, other participants, when asked by the researcher how they 'felt' in response to engaging in a particular health behaviour such as exercise for example, tended to respond in terms of what they 'did'. This type of response is likely to be due to difficulties some people with a learning disability have with abstract concepts and internal states (Finlay & Lyons, 2001). Some examples of this type of response, as well as others discussed below, can be found in Appendix H.

Furthermore some individuals appeared not to understand certain terms such as 'heart' when asked about these directly. As internal bodily organs are more abstract than external parts of the body, the use of drawings or photographs could have been employed to have made the anatomy more concrete, and thereby possibly have aided participants' understanding. However whilst the use of pictures, and more visual forms of communication are often viewed as useful tools to employ with people with a learning disability, there is research to suggest that this medium may not always be helpful (Cardone, 1999).
During the course of the interviews, despite efforts to monitor the language used, the researcher occasionally posed questions which were not as open as they could have been, or which contained words that lacked meaning to the participant. The contrast in the quantity and quality of information obtained when the researcher used vocabulary which was understood by the participants, demonstrated to the researcher the need, benefits and importance of using appropriate language when communicating with people with a learning disability. Furthermore during the piloting stage the researcher occasionally paraphrased the response of the participant. Whilst this practice was influenced by the researcher's clinical training, it acted to influence the participant's next response, and often resulted in the phrase or word being 'parroted' back. In the subsequent interviews the researcher was mindful about using this technique in view of the effect it had.

Occasionally participants made contradictory statements in the interview, and examination of the whole transcript sought to help clarify these. Furthermore throughout the interviews the researcher sought to remain alert to signs of any demand characteristics namely attempts at 'pleasing the researcher', which may have occasionally featured, as Grant's response possibly suggests (see Appendix H).

During the interviews there were occasions when the researcher had difficulty understanding the speech of some of the participants. When this occurred the researcher tended to repeat the word or sentence back to the participant. This form of response provided a means to check out that the researcher had heard the participant correctly, and also helped with the later transcribing of the interviews. However the researcher generally became more in tune with participants' speech as the interview progressed, and so such difficulties tended to be ameliorated.

Procedure

A further strength of the study was the informed consent procedure. This was influenced by the recommendations of Arscott et al. (1998), in which after the study had been introduced and the information sheet shown and discussed, participants were asked five simple questions to gauge their understanding and ability to give consent that was informed. Furthermore the researcher emphasised that there was no
obligation to take part in the research, and that individuals could stop taking part at any time or not answer questions they did not wish to. The researcher found that this occurred on two occasions, whereby firstly one individual who appeared interested and aware of the study and had answered the Arscott et al. (1998) questions, decided against participating when the consent form was introduced. The second occasion was during an interview in which a participant stated that they did not wish to talk further about the area under discussion, although was happy to proceed with a change of topic. Both instances gave the researcher some confidence that individuals felt comfortable with exercising their own choice and opinions during the research process.

The researcher found that in conducting research with people who have a learning disability that many systems were encountered, some of which had policies and procedures in place which conflicted with the research. For example it was the practice of one day centre not to release information regarding the individuals’ general practitioner without consent being given by the carers. This practice conflicted with the research consent procedure, in which individuals who gave their consent to take part in the research were simultaneously agreeing that their GP details could be acquired by the researcher. The researcher considered it important to respect the day centre’s practice. This difference was resolved in the form of the day centre offering to contact carers to obtain their consent in passing such details on to the researcher. Whilst this was only relevant to a small number of the participants, it still resulted in greater time being incurred in the data collection phase of the research.

The majority of the interviews were conducted on a one-to-one basis in which the researcher met independently with the participant after having obtained their consent. However one of the interviews involved a third-party being present at the request of the participant. This person was a professional who provided support to the participant in a mental health capacity, and was known to the researcher previously through one of her clinical placements. Whilst the presence of the third-party may have been reassuring for the participant, it is acknowledged that the dynamics will have been affected, and it is not known the extent to which this may have altered the responses the participant gave.
Reflexivity: the impact of the researcher

The position of the researcher was of a white married female, who was in the final year of postgraduate training to become a clinical psychologist. The researcher had prior experience of working with people with a learning disability, and had knowledge of literature pertaining to health and people with a learning disability, as well as more general psychological theory and research. These are factors which are acknowledged as influencing all aspects of the research process. However instead of constraining or restricting the research, the researcher sought to remain open to the ideas which emerged, although it is acknowledged that the beliefs and interests of the researcher, discussed under ‘owing one’s perspective’ will have influenced the research, for example through the questions that were asked. IPA fully acknowledges that the researcher is influential in the analytic process, and thus the findings are regarded as a co-construction between researcher and participant.

This research is considered as providing an important insight into how some people with a learning disability understand and experience health, as well as the behaviours they employ in order to help retain this state, and the factors which may impede them in achieving this. The clinical implications of this research, as well as possible avenues for future research are discussed below.

Clinical implications and avenues of future research

Evidence was found that certain areas of knowledge seemed to be particularly underdeveloped. These were related to the effects of exercise and a healthy diet upon participants’ health, particularly upon less visible areas such as the heart, and how exercise and a healthy diet might contribute to the reduction of certain health problems currently as well as in later life. Education aimed at raising understanding and awareness of these issues, namely the benefits of these behaviours seems warranted. These everyday behaviours would appear to be more of a priority than intervention geared towards the effects of smoking, given participants’ knowledge of and attitude toward this activity.

There was evidence to suggest that family members as well as other people such as carers, support staff, and medical professionals were very important in influencing the
individuals’ health behaviours. This research provides further evidence that a systemic approach is integral when working clinically to enhance the health of people with a learning disability. Part of this work may entail helping the system lessen their influence over the individual with the learning disability in order to help facilitate within the individual a greater sense of independence and responsibility over their health, and so enable greater self-efficacy to develop around engagement in particular health behaviours for example.

In order to access health care, participants considered there was a need for health problems to be present. As such, awareness needs to be raised regarding the preventative side to healthcare and greater emphasis placed upon opportunities to use healthcare as a means of preventing the occurrence of health problems, such as with check-ups and the use of screening for example.

Evidence of several barriers was provided by participants to engaging in healthy behaviours. Previous negative experiences seemed to exert a powerful influence over many participants’ health behaviours and influenced the choices they currently made. This area would seem important to examine with the individual, and may create new opportunities for engaging in healthy behaviours. Whilst removal of certain barriers may be possible, through working with the individual and alongside other agencies, it may be that some barriers, such as the choices the individual makes, as well as the influential systems which surround them remain, and these will need to be worked around clinically in order to enhance the individual’s health and quality of life.

When communicating with individuals who have a learning disability about health, particular attention should be paid towards the language used. This research adds weight for the need to use open questions wherever possible, to avoid paraphrasing the individual’s responses, and to use terminology which is both relevant and meaningful to the individual concerned. This seems to be particularly relevant for the systems which surround the individual with the learning disability, such as carers, support workers, as well as the GP, who may benefit from having their awareness raised regarding the importance of using certain types of questioning in order to facilitate more helpful forms of communication on the issue of health.
This study opens up several avenues for future research. For example the impact of employment upon health, and the health behaviours used could be explored, as could the influence of the individuals living situation. The role of the media in affecting people with a learning disabilities understanding of health could be examined, as could their understanding and attitude towards sexual health. Further exploration of the constructs employed in the models of health behaviour could also occur.

In summary this study investigated an extremely under-researched area. Little research has been conducted on how people with a learning disability understand and conceptualise health as well as the behaviours they engage in to be healthy, therefore this research was exploratory, and as such the conclusions drawn are tentative in nature. From the approach adopted this research generated data which may not have been achieved through quantitative methods. Indeed in line with qualitative research, it has not been the aim of this research to produce generalisable accounts, consequently information has been presented which seeks to inform others of the experiences of these particular group of adults with a learning disability. It is left to the reader to judge to whom and in what situations these findings may be considered relevant, and for further research to build upon this work.
References


Appendices

Appendix A: Background Information Form
Appendix B: Language assessment age equivalent scores
Appendix C: Interview Schedule
Appendix D: LREC & UniS Ethic Committee approval letters
Appendix E: Information Sheet
Appendix F: Consent Form
Appendix G: Letter to participants' GP
Appendix H: Methodological issues - some examples
Appendix I: Example transcript
Appendix A: Background Information Form
Name of participant .........................................................
This will be removed when a participant number has been assigned

__________________________________________________________ (Participant No.........)

BACKGROUND INFORMATION

Healthy behaviours in adults with a learning disability

This information is designed to provide greater details about the participant. All information will be treated in the strictest confidence, and destroyed following completion of the research.

1. Sex
☐ Male ☐ Female

2. Date of Birth..........................

3. Does the participant (please tick those that apply)
☐ Have a learning disability
☐ Use spoken language to communicate
☐ Have an autistic spectrum disorder
☐ Have dementia/suspected dementia

4. Type of School attended: (please tick one)
☐ Specifically for children with learning difficulties (moderate or severe)
☐ Mainstream School
☐ Other...........................................................................(please describe)

5. Current Living Arrangements: (please tick one)
☐ In a family home
☐ In a group home with carers
☐ Independently in the community
☐ Other .................................................................(please describe)

6. During the week does the participant (please tick those that apply)
☐ Attend a day centre
☐ Attend college
☐ Do paid work
☐ Do voluntary work
7. Name & Address of GP

8. Please provide brief details of any health problems known and how these are managed e.g. has poor eyesight so regular check-ups/wears glasses.

Thank you for providing this information. Please return to Jo Boulter in the envelope provided.
Appendix B: Language assessment age equivalent scores
Language assessment age equivalent scores

Age equivalents are provided in the table below in order to help further situate the sample for the reader\(^{10}\).

Table 4: Age equivalents of the language assessment scores

<table>
<thead>
<tr>
<th>Name</th>
<th>Renfrew Age Equivalent Scores (yy-mm)</th>
<th>BPVS Age Equivalent Scores (yy-mm)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Information</td>
<td>Grammar</td>
</tr>
<tr>
<td>Derek</td>
<td>8-04</td>
<td>5-09</td>
</tr>
<tr>
<td>Jason</td>
<td>4-10</td>
<td>3-09</td>
</tr>
<tr>
<td>Jessica</td>
<td>5-02</td>
<td>4-00</td>
</tr>
<tr>
<td>Mark</td>
<td>8-03</td>
<td>6-09</td>
</tr>
<tr>
<td>Laura</td>
<td>6-00</td>
<td>4-10</td>
</tr>
<tr>
<td>Lily</td>
<td>6-05</td>
<td>4-10</td>
</tr>
<tr>
<td>Andy</td>
<td>4-10</td>
<td>5-02</td>
</tr>
<tr>
<td>Sophie</td>
<td>3-06</td>
<td>3-05</td>
</tr>
<tr>
<td>Katie</td>
<td>7-00</td>
<td>7-03</td>
</tr>
<tr>
<td>Claire</td>
<td>3-09</td>
<td>4-02</td>
</tr>
<tr>
<td>Grant</td>
<td>3-09</td>
<td>4-02</td>
</tr>
<tr>
<td>Nigel</td>
<td>6-08</td>
<td>6-06</td>
</tr>
</tbody>
</table>

\(^{10}\) Whilst the researcher acknowledges the problems inherent in providing age equivalent scores for people with a learning disability, and disagrees with this practice, this information is offered as a means to help situate the sample further for the reader.
Appendix C: Interview Schedule
Interview Schedule

What does being healthy mean? (prompt: healthy i.e. well, not sick, ill)
How do you know/how can you tell when someone is healthy?
How healthy are you?
What healthy things do you do? (or What do you do to keep healthy i.e. well?)
How does X (identified activity/behaviour) help you/keep you healthy?
What do you like/not like about X (identified activity/behaviour)?
How do you keep your X healthy? (e.g. eyes, teeth, heart, lungs)
What people are important in keeping you healthy?
How does X (named person) help you keep healthy?
What can you do to make yourself healthier i.e. more healthy?
What might happen to you if you were less healthy?
What stops you being healthy? (or What healthy things don’t you do?, What stops you from X)
Tell me about a time when you stopped being healthy/well. What did you do/others do for you to be healthy again?
Appendix D: LREC & UniS Ethics Committee approval letters
MATERIAL REDACTED AT REQUEST OF UNIVERSITY
Appendix E: Information Sheet
INFORMATION SHEET

Healthy behaviours in adults with a learning disability

Joanne Boulter is doing some research, as part of her training to be a Clinical Psychologist. This means she needs to talk to lots of people. You are being asked to take part in the research. To help you decide if you want to take part you need to know more about the research and what you will be asked to do.

Please read this carefully. You can talk to other people about this like your family, friends, or support worker if you want to. You can ask Joanne if you have any questions, or want to know more. You can take your time to decide if you want to take part or not.

What is the research about?
Some people know a lot about being well, that is healthy. Other people know a little. Joanne wants to find out more about the things people with a learning disability know about being healthy, and what stops them being healthy.

Why have you been asked to take part?
You were chosen as you have a learning disability, and because you are good at talking to people. Altogether about 15 people will be taking part.

Do you have to take part?
It is up to you. You can say Yes or No. If you say Yes, Joanne will give you this sheet to keep, and a form to sign. If you say Yes now you can still say No later, and stop if you do not want to take part anymore. If you say No, this will not affect any services or help you are getting.

What will you be asked to do?
If you said Yes, you will be asked to: Tell Joanne the names of some pictures. Answer some questions about being healthy, and what stops you from being healthy. You will not have to answer any questions you do not want to. To help Joanne remember what has been said she will use a tape recorder.
Joanne will meet with you two times to do these things. Each time will last about one hour. This will be at a time and place that is okay for you.

**What are the possible disadvantages and bad things about taking part?**
You will use 2 hours of your time taking part. You may find some questions make you think of something bothering you. You can talk about this with Joanne, if you want to.

**What are the possible benefits and good things about taking part?**
It is important to find out more about being healthy to help improve the lives of people with a learning disability. By taking part you may be helping people in the future. You may also enjoy taking part.

**What about keeping things confidential?**
Your name and address will not be used in things that are written down. A special number will be used instead. The tape and all written details will be kept in a safe place. Only Joanne will listen to the tape. She will write down what was talked about. The tape will then be wiped clean.

The only time Joanne would tell someone about you would be if Joanne was worried that you or another person was not safe.

Joanne will let your GP know that you are taking part. Joanne will also collect some information from your support worker.

**What happens when the research is finished?**
After Joanne has spoken with lots of people she will write a report. This will be about the things she has found out. Nothing will be written about your private details, like your name or address. Joanne will give you details about what she has found out.

Thank you for reading this. Please contact Joanne if you have any questions.

Contact for further information:
Joanne Boulter, Trainee Clinical Psychologist
Tel: 01483 689441

The Local Research Ethics Committee has approved the above statement.
1.10.2003/Version 2
Appendix F: Consent Form
CONSENT FORM

Title: Healthy behaviours in adults with a learning disability

Name of researcher: Joanne Boulter*

I .............................................................. (name) would like to take part in this research.

Please tick box √

I have read and understand the information sheet. I have been able to ask questions if I wanted to.

I know that by saying Yes now to taking part I can still stay No later. I can stop taking part any time I want.

I know that my GP will be told that I am taking part, and that some details will collected from my support worker.

Yes I want to take part in this research.

Name of participant   Date       Signature

Witness               Date       Signature

Researcher            Date       Signature

Participant identification number .........
1.10.2003/Version 2
*This research is being completed as part of a Clinical Psychology course at the University of Surrey
Appendix G: Letter to participants' GP
<Name of GP>
<Address of GP>

<Date>

Dear <Name of GP>

Re: <Name of participant, & Date of birth>
<Address of participant>

I wish to inform you that the above named has agreed to participate in the following research: 'Healthy behaviours in adults with a learning disability'. The research intends to explore what people with a learning disability understand about healthy behaviours e.g. taking exercise, eating 'healthy' foods, not smoking, and what factors may stop or hinder them from engaging in these healthy behaviours. I enclose a participant information sheet giving further details of the study for your information.

Please inform me if this patient is involved in another research study, or if you consider there to be medically relevant information of which I should be made aware. If you would like to discuss any aspect of this further please do not hesitate to contact me.

Yours sincerely

Joanne Boulter
Trainee Clinical Psychologist
Principal Investigator
Appendix H: Methodological issues - some examples
Methodological issues - some examples

Some participants when asked about how they 'felt' tended to respond in terms of what they 'did', as shown by the examples provided by Jessica and Andy below.

I: Oh right, that's good. So how do you feel when you are healthy?
P: You can go around can't you, find things to do

I: And how did you feel when you got better?
P: Get out of bed and go to work.

On one of the earlier interviews, the paraphrasing of the researcher subsequently influenced the response of the participant, as shown through Jason's adoption of the terminology used by the researcher, firstly in terms of the medication routine he had become accustomed to, and then in terms of obtaining a balance between healthy and perhaps slightly less healthy food:

I: Right, so you've got into a bit of a routine?
P: Routine of taking tablets, yeah.

P: That's my treat. I buy curry now and again. But I know it's not good for you, it's bad for you. As I said, you've got to have something bad, got to have something good.
I: So it's a bit of a balance for you
P: A balance, you could say that, a balance of good, a balance of bad.

Occasionally participants contradicted themselves within the response they had just given. For example Andy identified the involvement of his mother in helping him keep healthy as she took him shopping which he identified as good for you, although his response explaining how shopping was good for you seemed to be somewhat contradictory:
I: Oh your mum? How does she keep you healthy?
P: _She takes me shopping, that's good for you._
I: How is shopping good for you?
P: _It's heavy_
I: How is it good for you then?
P: _Not good for your back_
I: Not good for your back?
P: _You can hurt yourself_

Similarly Jason provides a contradiction in terms of who he was with at the pub:

P: _Last night I was out in a pub on my own. I had half a pint of cider and a glass of wine. I couldn't drink another one, it's 12%, it's too strong. I said I can't drink this I'm on pills. I gave it to Dwayne..._

The researcher sought to remain alert for any signs of acquiescence, and attempts to 'please the researcher' within the interviews. This seems to feature within Grant's response, as when asked about what else he did to keep healthy he described how he walked to work, although then modified his response, perhaps in an attempt to present a healthier account to the researcher:

I: What else do you do to keep healthy?
P: _I do walk to work, and catch the...just walk to work really._
Appendix I: Example transcript
Example transcript

1. I: Tell me, what does 'being healthy' mean?
2. P: Eat healthy food.
3. I: Mmm
4. P: And, umm, don't eat the wrong food.
5. I: Yeah. So, what sorts of foods are healthy?
6. P: Sometimes biscuits, some biscuits.
7. I: What sorts of biscuits?
9. I: Oh right, yeah.
10. P: That's all I can think of
11. I: Okay, what foods aren't healthy?
12. P: Like, um, chocolates, bread, and umm sugar.
13. I: Right
14. P: And lots more
15. I: So these foods are bad for you. What makes them bad?
16. P: They rot your teeth.
17. I: They rot your teeth, okay. So what healthy things do you do?
18. P: I make myself a sandwich. Drink a lot of cups of tea. Like, eat and drink healthy food, drink healthy drink and stuff.
19. I: So you make yourself sandwiches? What do you have in your sandwiches?
20. P: Ham, or cheese and pickle.
21. I: So what sort of bread do you use for your sandwiches?
23. I: Brown bread. Is brown bread any different from white bread?
24. P: Brown bread is good for you, white bread is not good for you.
25. I: Right, how come the brown bread is good for you?
26. P: I'm not sure on that one. (pulls worried face)
27. I: You're doing fine, so for you Grant, you eat healthy foods. What else do you do to keep healthy?
28. P: I do walk to work, and catch the... just walk to work really.
29. I: You walk to work. That sounds good. How does that keep you healthy?
P: It just does.
I: Mmm, is that something that you like doing?
P: Yeah.
I: Yeah. How does your body feel after you’ve walked to work?
P: Sometimes tired, sometimes lively.
I: Right, so sometimes you might feel tired, sometimes you might feel lively. So what might happen to your body if you didn’t walk to work? Say if you got the bus there every time. Do you think you would be as healthy or less healthy?
P: Less healthy, less healthy.
I: Less healthy. You said that chocolate and sugar are not good for you. What would happen if you just ate that?
P: You’d be stuck with chocolate all day.
I: Yeah. You’d be stuck with chocolate all day. What people are important in keeping you healthy? Is there anyone who’s important in keeping you healthy do you think?
P: Your family, and the people who you work with, and your friends.
I: Okay, so how do your family keep you healthy?
P: They buy sometimes healthy food for me, and make healthy food for me at home. I just make myself cups of tea and stuff.
I: Yeah, so they buy food, and you make some food as well, that sounds good. What about, you said people at work help you, how do they keep you healthy?
P: They ask every time at work if I can have a break and that, just have a cup of tea and that
I: Okay. You said your friends also keep you healthy. How do they do that?
P: Um, we used to go for a bike ride. I haven’t got a bike any more, so.
I: What happened to your bike?
P: It was quite a while ago. I was about to go to work. I was riding my bike and felt a bit dizzy and I fell off my bike and had to go to hospital, and I accidentally left my bike there.
I: Oh did you, oh dear.
P: So I won’t be riding my bike any more.
I: That doesn’t sound very nice, what happened to you there Grant. How did you get better again?
P: I just kept walking to work, in the end and to the bus station and back home.

I: Okay. So when you went biking, what did you like about biking?

P: You just go fast, and that's all, going fast.

I: How did that make you feel?

P: More like lively

I: Lively, yeah. How did it help your body? What was it doing?

P: More like, your legs were doing most of the work.

I: Your legs were doing most of the work, okay. Did they ache?

P: No.

I: You must have been very fit then!

P: Yeah.

I: So now that you don't go biking, do you do anything else instead, any other sorts of exercise?

P: If there's a lot, if there is anything outside that needs doing, I help Mum outside in the garden sometimes.

I: Oh right. Is that something you like doing?

P: Sometimes.

I: Sometimes, okay. How can you tell when you are healthy? How do you know when you are healthy?

P: Just tell inside your head.

I: Inside your head, yeah. So how healthy would you say you are then?

P: Bit of both.

I: Bit of both, yeah. So tell me about the bit that's healthy then, and tell me about the bit that is not so healthy.

P: Healthy, my heart is healthy, my stomach is healthy. In here, that's not. (points to head)

I: In here, in your head?

P: My head, sometimes I'm tired.

I: You're tired?

P: Sometimes I'm not, but sometimes I'm tired.

I: Mmm.

P: And the rest of it's fine.
I: The rest of it is fine, yeah. So when are the times when you are not tired? When
are they?

P: Weekends.

I: What happens at weekends?

P: Um, well not all the time, but occasionally at weekends, Saturday nights, we order
a curry, or watch TV or videos. That's about it on Saturday, but on Sunday we're
busy doing housework and umm, that's about it really.

I: But, the curry and the video, that's something that you like?

P: Yeah.

I: I see. How do you look after your body? You mentioned walking. Is there
anything else you do to look after it?

P: I used to take the dog for a walk.

I: Oh yeah.

P: I did it quite a while ago, quite a long time ago now, quite a long time ago. When I
took the dog for a walk it was like, we went up the field, and were playing on the
swings. There were lots of cars there, and people getting in their cars. I told the dog
to stay with me, but she kept on pulling her lead, and I got to mother and a little kid,
and she said to me 'Is this dog alright?' and I said yeah. The boy came up to the
dog, and the dog started barking loudly to the boy. She kept on just going really fast
and I couldn't hold her. She's a bit naughty sometimes, sometimes good. So I'm not
particularly keen on walking dogs.

I: Okay, what about your teeth, how do you keep your teeth healthy?

P: Clean them every day.

I: Mmm.

P: I always clean my teeth every day and evenings

I: What would happen if you didn't clean them?

P: Your teeth would start to rot, or get black bits.

I: Black bits, yeah. What about your eyes Grant? How do you keep your eyes
healthy?

P: Wearing glasses.

I: Mmm.

P: I used to but I'm getting some tomorrow

I: Oh right, what's it like wearing glasses?
P: If you wear it like, a big pair of glasses, then the big bits can hurt you and can dig into your nose. That's what happened to me once. I had a big spot there where they dug in and now I'm getting real small ones.

I: Oh, so that's going to be better for you then. What about your heart Grant? How do you keep your heart healthy?

P: Running

I: Running?

P: Running and walking as well, just running and walking.

I: How does that keep your heart healthy?

P: Not sure

I: Do you go running?

P: Used to go running, not any more.

I: How come you stopped running?

P: Because my friends have grown up now and they do other things.

I: Oh right.

P: I'm always, sometimes at home, have been at home.

I: Okay, what about your lungs, how do you keep your lungs healthy?

P: Not sure on that one.

I: That's fine. You mentioned that there are some people, your family and friends and people at work that help keep you healthy. Do they do healthy things that you don't?

P: Not really, no.

I: Not really, no? Do they do unhealthy things that you don't, like smoking?

P: My family smokes, my sister. I don't want to.

I: How come you don't want to?

P: If you smoke too much it will kill you. And, that's it, it's bad.

I: Okay, tell me about a time when you haven't been well, when you stopped being healthy.

P: Umm, it just happens, I just get dizzy spells sometimes.

I: Oh right, you get dizzy spells.

P: And, um, I just get dizzy spells

I: What do you have to do when you have them? Do you have to sit down or...

P: Last time I was on the bus, I was sitting on the bus and I felt my head and eyes watering. When we got to the Spar, I got up but I couldn't walk, and the bus was
carried on driving. I was walking through the bus, and I found another seat ’cause I couldn’t see. When we got to Waitrose and Spar, I found a seat and somebody told the bus driver to stop, and a man told me am I alright? I couldn’t talk, I said to him I’m a bit dizzy, so they called an ambulance and they gave me a drink of water and a Mars Bar.

I: Oh right
P: So I went to hospital, and then I was better then.
I: How did you get better?
P: Um, the ambulance man, ’cause they put that thing on my mouth, a mask and umm they asked me where do I live, and I told them, [place] and they brought me back home, so that’s how I got better.
I: Oh, right, and how did you feel when you were better again?
P: Tired.
I: Okay, that doesn’t sound very nice. What about, what things stop you being healthy?
P: Chocolate
I: Chocolate? You like chocolate? What do you have?
P: I like most of them with 2 chocolates like a Twirl and Time Out.
I: Oh yeah
P: My sister drives a car, and when she goes to the shops to get a newspaper and cigarettes sometimes I ask her and she’ll get me a chocolate bar. And she gets me something like a Time Out. That’s the best.
I: Is there anything else that might stop you being healthy?
P: Not really, no
I: No? What might happen to you if you weren’t so healthy? You told me that you were a bit of both, a bit healthy and a bit not-so healthy. What might happen if you weren’t so healthy?
P: Probably I’d be ill and collapse and stuff like that. That’s about it.
I: Oh, okay. Now I know you said earlier about biscuits and things you like eating. I was going to ask about other foods that keep you healthy. What are they?
P: (pulls worried face)
I: Not sure?
P: Not sure.
I: You said you like to drink tea as well. What other drinks are there that help keep you healthy?
P: Not healthy are coke and fizzy drinks. We do get fizzy drinks on Thursdays. Coffee is good for you, so are orange and lemon, blackcurrant, and strawberry. That’s all I can think of.
I: That’s fine. Are there any other things that you do during the day that keep, that are good for you?
P: Well, I like playing my games a lot. I’ve got a PlayStation 2 game.
I: Oh, right.
P: And, um, or watching wrestling. I’m a big fan of wrestling.
I: You’re a big fan of wrestling? Oh right.
P: And, umm, or watch DVDs. I’ve got a DVD player. I like Stephen King films, and I listen to music.
I: You listen to music? So in what way are these things good for you then?
P: Music is good for you because there is all the singing and dancing. That’s about it really. My favourite kind of music I like is rock and indie stuff.
I: Oh right
P: I like StarSaver, The Darkness, and Nickleback. That’s about it music. And games, and video games sometimes is good for you, sometimes is not. It’s just entertaining to play and to watch.
I: So, it’s entertaining then. How do you feel afterwards? After listening to the Darkness?
P: Um, I go downstairs, and watch video and TV.
I: Okay, What can you do to make yourself more healthy?
P: More running. I mention it but I don’t do it any more, ride bikes.
I: Yeah, so that’s something you’d like to do more of?
P: Yeah. Um, and listen to music, and that’s about it.
I: Well, we are coming towards the end. (pause) Is there anything else that we haven’t talked about in terms of keeping healthy? Anything else you’d like to talk about?
P: No
I: No? Okay, well thank you Grant. I shall turn the tape off now.
LOG OF RESEARCH EXPERIENCE

Below is a list of examples of research skills which you are encouraged to gain experience in during your training. You should obtain a copy of the outline on a WORD file on disk from the Course Administrator (you provide the disk). You should use this outline format to keep this log up to date as you progress through the course. It should serve as a record of your research experience and skills and should be able to be printed out at fairly short notice in order to update your research tutor on your progress, and to assist at the Mid-Course Review. The list is not exhaustive, and so where you have gained experience of a particular type of research activity you should check if it fits into one of the categories already inserted in the framework. If it is not already on the list then add a new category and appropriate description of your experience.

It is intended that the final log will be inserted into your Research Dossier of your final portfolio and should demonstrate to the examiners what research skills and experiences you have acquired (in addition to that shown in the research reports required for the research dossier).

<table>
<thead>
<tr>
<th>Research Skill/Experience</th>
<th>Description of how research skill/experience acquired</th>
<th>Date research skill/experience acquired</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conduct a literature search</td>
<td>Conducted literature searches throughout training for essays, case reports, clinical work and research. Used a range of tools including: PsychInfo; PsychLit; and Medline.</td>
<td>Oct/Nov 2001</td>
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<td></td>
<td>Service Related Research Project: Conducted a computerised literature search on the topic of women survivors of sexual abuse attending group therapy using psychlit.</td>
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<td></td>
<td>Learned how to combine and exclude key words in literature search. The searches included several possibly relevant references–obtained a print out of the details relating to these articles including the abstracts.</td>
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<tr>
<td>Research Logbook</td>
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<tr>
<td><strong>Critically review the literature</strong></td>
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<tr>
<td>Major Research Project: The literature on healthy behaviours within adults with a learning disability was critically reviewed. As well as published research articles, book chapters, and unpublished doctoral thesis were consulted to obtain as up-to-date a reflection of the knowledge base. It appeared that considerable gaps existed within the literature for this client group.</td>
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<tr>
<td>Qualitative Group Project: Critically reviewed the literature on personal therapy during clinical psychology training and discussed this with other trainees involved in the group project.</td>
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<td><strong>Formulate a specific research question</strong></td>
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<tr>
<td>Service Related Research Project: Decided to conduct an audit of a survivors of sexual abuse group in terms of the characteristics of women who complete/dropout of treatment, after discussion with AMH placement supervisor, and following consultation with research tutor. The primary research question was to examine whether there were significant differences in the abuse histories of women who completed the group compared to those who dropped out of the group. Differences in the social supports of women who completed the group compared to those who dropped out of the group was a further research question posed.</td>
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<tr>
<td>Major Research Project: Following a review of the published knowledge base regarding the health of people with a learning disability I decided to undertake an</td>
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<tr>
<td>Activity</td>
<td>Description</td>
<td>Date</td>
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<tr>
<td><strong>Write a brief research proposal</strong></td>
<td>Service Related Research Project: A brief research proposal was written, submitted and subsequently approved by both field and research supervisors. Major Research Project: A brief research proposal was written and submitted to the course team, and approval obtained to proceed with the research.</td>
<td>December 2001-Oct/Nov 2002</td>
</tr>
<tr>
<td><strong>Write a detailed proposal/protocol</strong></td>
<td>Major Research Project: A detailed protocol regarding the research was written, which included a detailed rationale for the project, copies of all proposed correspondence such as letters to the GP, Information Sheet and Consent Form. This was submitted to the Trust R&amp;D advisor and following approval it was then sent to the local Trust Ethics Committee where it received full approval at first submission. The detailed protocol was also submitted to the University of Surrey Advisory Committee on Ethics, and was approved following a minor amendment.</td>
<td>June 2003-August 2003</td>
</tr>
<tr>
<td><strong>Obtain appropriate supervision/collaboration for research</strong></td>
<td>Service Related Research Project: Discussed proposed service related research project with supervisor on placement, who became field supervisor. Supervision was also acquired from a university research tutor. Major Research Project: Supervision was obtained at all stages of the research process from the university research supervisor and field supervisor. Peer supervision was</td>
<td>November 2001-September 2002-June 2004</td>
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<td>Research Logbook</td>
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<td>also acquired from a qualitative research group specifically for trainees using IPA. The group consisted of 6 research peers who were using IPA and 2 research tutors, who were both experienced in qualitative research. A particular feature of the group was the analysis of data from the transcripts and discussion regarding the themes that emerged. Qualitative Group Project: Sought advice regarding the research from the lecturer who was an established qualitative researcher. Furthermore working in a group enabled peer supervision and facilitated collaborative working of the shared tasks.</td>
<td>April 2004-June 2004</td>
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<tr>
<td>Write a participant information sheet and consent form</td>
<td>March/April 2003</td>
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<tr>
<td>Qualitative Group Project: A participant information sheet and consent form were devised for the qualitative research. Major Research Project: A participant information sheet and consent form were written. When devising this consideration was given to local Trust Ethics Committee guidelines, as well as the language ability of the recipients i.e. people with a learning disability. Terminology was used which was thought to be at an appropriate level, and the Flesch readability measure applied to gauge the degree of reading ease. Consultation was also sought from appropriate supervisors.</td>
<td>March 2003</td>
<td>May 2003</td>
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<tr>
<td>Judge ethical issues in research and amend plans accordingly</td>
<td>January 2002</td>
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<tr>
<td>Service Related Research Project: Following feedback from the Trust’s Clinical Audit/R&amp;D advisor the assessment forms were anonymised prior to being used for the research, to protect confidentiality of the women survivors. Qualitative Group project: Participants were assured of the confidential nature of the research, and that all details would be anonymised. Furthermore all information would be stored securely and held for no longer than was necessary. The tape-recording would be destroyed after use. Participants were aware of their right to withdraw at any time. Major Research Project: As informed consent is a significant issue in research with</td>
<td>April 2003</td>
<td>June 2003</td>
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<td>Task</td>
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<tr>
<td>Obtain approval from a research ethics committee</td>
<td>Major Research Project: Ethical approval was granted following first submission to a Local Research Ethics Committee. In addition approval was obtained from the University Advisory Committee on Ethics.</td>
<td>July 2003, September 2003</td>
</tr>
<tr>
<td>Collect data from research participants</td>
<td>Qualitative Group Project: A semi-structured interview was conducted with a third year trainee. This was tape recorded and later transcribed verbatim. Major Research Project: Semi-structured interviews occurred with adults with a learning disability, which were tape-recorded and then transcribed verbatim.</td>
<td>April 2003, January-March 2004</td>
</tr>
<tr>
<td>Set up a data file</td>
<td>As part of course teaching on research and statistics data files were regularly created on SPSS. Service Related Research Project: In order to analyse the information a large computerised data file on SPSS was set up.</td>
<td>September 2001-June 2002, April 2002</td>
</tr>
<tr>
<td>Analyse quantitative data</td>
<td>Service Related Research Project: The data was analysed using chi square and independent t-tests, and the significance of the results obtained. Descriptive statistics were also used.</td>
<td>April 2002</td>
</tr>
<tr>
<td>Analyse qualitative data</td>
<td>Service Related Research Project: Performed a content analysis on the qualitative data within the assessment forms. Used an independent rater to establish the inter-rater reliability of the categories constructed (=0.95).</td>
<td>May 2002</td>
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<td>Task</td>
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<tr>
<td>Summarise results in figures/graphs</td>
<td>Service Related Research Project: Results were summarised in tabular and also graphical format using SPSS. Qualitative Group Project: A diagram depicting the relationship between the themes which emerged was presented in the report.</td>
<td>April 2002</td>
</tr>
<tr>
<td>Interpret results from data analysis</td>
<td>Service Related Research Project: The results were interpreted from the data analysis. Qualitative Group Project: The results of this project were interpreted as a group. Major Research Project: The results were interpreted from an analysis of the qualitative data, and themes discussed at an IPA group.</td>
<td>April 2002, April 2003, May 2004-June 2004</td>
</tr>
<tr>
<td>Present research findings/plans to an audience</td>
<td>Service Related Research Project: The presentation of the results to the psychology department, which included the field supervisor was planned, however the meeting was cancelled by the department at very short notice. A short written summary of the results was subsequently provided along with a copy of the report. The content and process of the service related research project was also presented to first year trainees and course staff. Major Research Project: The content and process of the major research project was presented to second year trainees and members from the course team. Furthermore a presentation of the planned major research project occurred to staff at 'EmployAbility', a specialist service for people with a learning disability, to heighten their awareness of the project and generate possible participants for the research.</td>
<td>July 2002, October 2002, September 2003, October 2003</td>
</tr>
<tr>
<td>Produce a written report</td>
<td>Service Related Research Project: A 3000 word report was produced on the</td>
<td>May 2002</td>
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<td>on a research project</td>
<td>characteristics of women who attend/drop out of a survivors of sexual abuse group for the service related research project. Qualitative Group Project: A 3500 word report was produced on the desirability of personal therapy during clinical psychology training for the qualitative group project. Major Research Project: A 20000 word report was written regarding adults with a learning disabilities understanding and experience of being healthy. A summary document detailing the findings of the research will also be given to participants and services involved in the research.</td>
<td>May 2003</td>
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<tr>
<td>Defend research project at an oral examination</td>
<td>Major Research Project: This is planned for September 2004.</td>
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<tr>
<td>Submit research report for publication in a journal/book</td>
<td>Major Research Project: This is intended to be submitted for publication to a journal.</td>
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