# Factors affecting the provision of psychological therapy to people with learning disabilities in the NHS

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#### **Abstract**

People with learning disabilities are known to be at increased risk of developing mental health problems. The reasons for this vulnerability are unclear, and a range of biological, sociocultural, cognitive, systemic and psychodynamic explanations have been forwarded. Further, although a significant amount of research has been focussed on psychological therapies for mental health problems, until recently little attention has been given to their application to people with learning disabilities. This, in combination with a number of other factors (such as a historical trend to suppose that people with learning disabilities struggle to make use of psychological therapy), means that this client group has relatively little access to therapy services.

Five factors were proposed to affect the provision of psychological therapy to people with learning disabilities: service resources, the perceived effectiveness of psychological therapy with this client group, the perceived individual competence of clinicians in administering psychological therapy to this client group, the level of the client's disability and the diagnostic overshadowing bias. Psychologists and psychiatrists working in learning disability services throughout the UK were sent a questionnaire examining the 5 factors proposed above. 133 psychologists and 90 psychiatrists (32% response rate) returned completed questionnaires.

Perceived individual competence was found to be the most consistent predictor of the provision of psychological therapy to people with learning disabilities. Service resources and effectiveness emerged as important in the case of systemic therapy and psychodynamic therapy, although only marginally so. Clinicians appeared to consider psychological therapy less appropriate, harder to do and less effective as the level of the client's disability increased. In addition, diagnostic overshadowing appeared to be influencing the way in which clinicians appraised the symptoms of mental health problems in people with learning disabilities

The significance of these findings is discussed in light of both recent clinical research and current developments in healthcare policy for people with learning disabilities.

| CHAPTER 1: INTRODUCTION  | 1                          |
|--|----------------------------|
| SOME REASONS FOR NEGLECT   | 1                          |
| HISTORICAL FACTORS   | 1                          |
| THEORETICAL AND CLINICAL PROBLEMS  | 4                          |
| DO PEOPLE WITH LEARNING DISABILITIES NEED PSYCHOLOGICAL THERAPY?   | 9                          |
| THE PREVALENCE OF MENTAL HEALTH PROBLEMS IN PEOPLE WITH LEAF DISABILITIES  |                            |
| AETIOLOGY OF MENTAL HEALTH PROBLEMS IN PEOPLE V<br>LEARNING DISABILITIES   |                            |
| ORGANIC FACTORS  |                            |
| BEHAVIOURAL FACTORS  |                            |
| DEVELOPMENTAL FACTORSSOCIOCULTURAL FACTORS   |                            |
|  |                            |
| EVIDENCE FOR THE EFFECTIVENESS OF PSYCHOLOGICAL THERAPY FOR PEOPLE WITH LEARNING DISABILITIES  |                            |
| INTERVENTIONS BASED ON LEARNING THEORY   |                            |
| COGNITIVE BEHAVIOUR THERAPY  |                            |
| PSYCHODYNAMIC PSYCHOTHERAPIES  |                            |
| SYSTEMIC INTERVENTIONS   |                            |
| GROUP APPROACHES   | 23                         |
| HOW IS PSYCHOLOGICAL THERAPY USED WITH PEOPLE V<br>LEARNING DISABILITIES?  |                            |
| FACTORS AFFECTING THE PROVISION OF PSYCHOLOGICATHERAPY TO PEOPLE WITH LEARNING DISABILITIES  |                            |
| SERVICE RESOURCES  |                            |
| EFFECTIVENESS OF PSYCHOLOGICAL THERAPY   |                            |
| PERCEIVED THERAPEUTIC COMPETENCE   |                            |
|  |                            |
| LEVEL OF DISABILITY  |                            |
| DIAGNOSTIC OVERSHADOWING   |                            |
|  |                            |
| DIAGNOSTIC OVERSHADOWING   | 36                         |
| DIAGNOSTIC OVERSHADOWING   | 36                         |
| DIAGNOSTIC OVERSHADOWING   | 36<br>37                   |
| DIAGNOSTIC OVERSHADOWING  RESEARCH QUESTIONS  CHAPTER 2: METHOD  PARTICIPANTS  MATERIALS   | 36<br>37<br>38             |
| DIAGNOSTIC OVERSHADOWING  RESEARCH QUESTIONS  CHAPTER 2: METHOD  PARTICIPANTS  MATERIALS  CONSTRUCTION OF THE QUESTIONNAIRE  ATTITUDE SURVEY   | 36373838                   |
| DIAGNOSTIC OVERSHADOWING  RESEARCH QUESTIONS  CHAPTER 2: METHOD  PARTICIPANTS  MATERIALS  CONSTRUCTION OF THE QUESTIONNAIRE  ATTITUDE SURVEY  Table 1: Items included in the 3 subscales | 36<br>37<br>38<br>38<br>39 |
| DIAGNOSTIC OVERSHADOWING  RESEARCH QUESTIONS  CHAPTER 2: METHOD  PARTICIPANTS  MATERIALS  CONSTRUCTION OF THE QUESTIONNAIRE  ATTITUDE SURVEY   | 36<br>37<br>38<br>38<br>39 |
| DIAGNOSTIC OVERSHADOWING  RESEARCH QUESTIONS  CHAPTER 2: METHOD  PARTICIPANTS  MATERIALS  CONSTRUCTION OF THE QUESTIONNAIRE  ATTITUDE SURVEY  Table 1: Items included in the 3 subscales | 363738383940               |

| FOLLOW-UP INTERVIEWS   | 43    |
|--|-------|
| ETHICAL APPROVAL   | 43    |
| CHAPTER 3: RESULTS   | 45    |
| CHARACTERISTICS OF THE SAMPLE  | 45    |
| DATA SCREENING   | 45    |
| DEMOGRAPHIC FEATURES   | 45    |
| Table 2: Demographic features of sample  | 46    |
| TYPE AND AMOUNT OF THERAPY PROVIDED  |       |
| Table 3: Summary of therapies provided to people with learning disabilities  | 47    |
| SERVICE RESOURCES, EFFECTIVENESS AND COMPETENCE .  | 47    |
| SERVICE RESOURCES  Table 4: Mean resources available (as rated by respondents) to learn  | 47    |
| disability services in the UK  | 48    |
| COMPETENCE AND EFFECTIVENESS   |       |
| THE INFLUENCE OF PERCEIVED EFFECTIVENESS, INDIVIDUAL COMPETENCE  | E AND |
| SERVICE RESOURCES ON PROVISION OF PSYCHOLOGICAL THERAPY  |       |
| Table 7: Summary of regression model for affect of competence, effectiveness and service resources on psychologists only               |       |
| effectiveness and service resources on the provision of CBT, psychodynamic, systemic and group therapy                                 | 54    |
| THE INFLUENCE OF LEVEL OF DISABILITY   |       |
| Table 9: The effect of level of disability   |       |
| THE INFLUENCE OF THE DIAGNOSTIC OVERSHADOWING BI   |       |
| Table 10: The effect of type of vignette on diagnosis  | 59    |
| Table 11: The effect of role on diagnosisFigure 1: Ratings of schizophrenia by role and type of vignette                               | 61    |
| Figure 2: Ratings of drug problems by role and type of vignette<br>Figure 3: Ratings of need for MHA assessment by role and type of vi | 62    |
| 1 squire 3. Italings by need for 171111 dissessment by rote and type by ro   |       |
| CHAPTER 4: DISCUSSION  | 64    |
| MAIN FINDINGS  | 64    |
| CASE FYAMDI ES   | 65    |

| THE CURRENT STATUS OF PSYCHOLOGICAL THERAPY FOR PEOPLE WITH LEARNING DISABILITIES  | 65             |
|--|----------------|
| THE USE OF DIFFERENT PSYCHOLOGICAL THERAPIES WITH PEOPLE WITH LEARNING DISABILITIES  |                |
| Table 12: Case example 1: working with people with learning disability using psychodynamic approaches  |                |
| COMPETENCE, EFFECTIVENESS AND SERVICE RESOURCES  | 70             |
| PERCEIVED INDIVIDUAL COMPETENCE  PERCEIVED EFFECTIVENESS OF PSYCHOLOGICAL THERAPY  Table 13: Case example 2: the role of perceived competence and effectiveness  SERVICE RESOURCES | 73<br>76       |
| THE ROLE OF LEVEL OF DISABILITY  | 78             |
| Table 14: case example 3: Psychological therapy with people with sevel learning disabilities.  CAN PSYCHOLOGICAL THERAPY HELP PEOPLE WITH SEVERE AND PROFOUNI DISABILITIES?        | <i>80</i><br>O |
| THE SIGNIFICANCE OF THE DIAGNOSTIC OVERSHADOWING BIAS  | 84             |
| LIMITATIONS OF THIS STUDY  | 86             |
| CLINICAL IMPLICATIONS  | 91             |
| CONTINUING PROFESSIONAL DEVELOPMENT (CPD)  | 92             |
| AREAS FOR FUTURE RESEARCH  | 93             |
| REFERENCES   | 95             |
| APPENDIX 1: LETTER TO REGIONAL SPECIAL INTEREST GRO  |                |
| APPENDIX 2: CONSENT FORM   |                |
| APPENDIX 3: INFORMATION LETTER   | . 117          |
| APPENDIX 4: ETHICS APPROVAL  | . 118          |
| APPENDIX 5: QUESTIONNAIRE  | . 119          |
| Questionnaire: Psychological Therapies with people with Learning DisabilitiesLearning disability IO vignette   | . 120<br>. 126 |

#### **Chapter 1: Introduction**

Few would now disagree that the emotional lives of people with learning disabilities have been relatively neglected within the theoretical and clinical literature (see, for example, Bender, 1993; Matson and Barrett, 1982; Matson and Sevin, 1994). The aim of this chapter is to examine how this may have developed, to evaluate the role that psychological therapy can play in helping people with learning disabilities who have mental health problems and finally to outline the factors that this thesis proposes as important in determining the provision of psychological therapy to this client group.

#### Some reasons for neglect

As the principal aim of this thesis is to examine contemporary attitudes to the treatment of mental health problems in people with learning disabilities, it is useful to consider the roots of some of the negative attitudes that may still exist. Briefly, it will be argued that this is likely to be the product of a number of interacting factors:

- Historical approaches which emphasised the containment rather than the care of people with learning disabilities, and viewed people with learning disabilities with disdain or as 'eternal children'.
- The emergence of different therapeutic approaches and the theoretical reorganisation of some existing approaches.

#### **Historical factors**

Wolfensberger (1972) identified eight roles that, historically, have been assigned to people with learning disabilities. These include portrayal as a subhuman organism, as a menace, as an unspeakable object of dread, as an object of pity, as a holy innocent, as a diseased organism, as an object of ridicule and as an eternal child. Wolfensberger (1972) argues that, as people are assigned these

roles, so they begin to take on some of their characteristics. Thus, society's portrayal of people with learning disabilities creates a group who begin to view themselves in a series of extremely negative ways. Importantly, Wolfensberger also argues that much of this process is unconscious, making its way into the collective unconscious via literature, art, popular myth and the media. Wolfensberger notes that, prior to normalisation (the principle that people with learning disabilities should have equal access to as normal a lifestyle as possible), society managed people with learning disabilities in one of four ways: destruction, segregation, treatment or prevention. Thus, it is possible to see how, through the propagation of such negative notions of people with learning disabilities, their emotional lives and mental health needs were easily neglected.

Caine, Hatton and Emerson (1998) note that an historical analysis of the development of services for people with learning disabilities in general provides a sobering perspective on the current style of service provision, principally because it shows how themes of community care and institutional care repeat themselves. History shows, for example, that services have changed from a community care model in the period leading up to the nineteenth century; the development of asylums in the Victorian era which subsequently become the large institutions of the early twentieth century and finally a transition back to a more community care-oriented model of service provision.

Importantly, the progression of services for people with learning disabilities reflects changing social practices and attitudes. The initial reasons for the development of asylums in the early part of the nineteenth century reflected changes in family structures and family economies, changing conceptions of mental illness and 'idiocy' and the development of more philanthropic Victorian ideals (Scheerenberger, 1983). Thus, the first institutions were founded on the basis of a new optimism about the possibilities of teaching new skills to people previously thought of as 'uneducable' (Gladstone, 1996). However, as demand for places rose, economies of scale resulted in the development of larger and larger institutions. What began as a collection of small, voluntarily run asylums for children quickly developed into a collection of enormous, state-run institutions. Adults were retained as a way of providing cheap labour, and some

authors (e.g. Gladstone, 1996; Jackson, 1996) have argued that this itself lead to the development of an ethos of permanent containment.

By the end of the nineteenth century several strands of thought were converging to reconceptualise people with learning disabilities as a threat to society. While society watched the population of the institutions swell at an alarming rate, the eugenics movement and social Darwinism took hold. Fear spread that people with learning disabilities would propagate at such a rate as to overwhelm society with 'defective' people, and the permanent segregation of people with learning disabilities ('mental deficiency') became an explicit goal of the state. This was embodied in legislation, with the recommendations of the Royal Commission on the Care and Control of the Feeble-Minded (1904-8) being formalised in the Mental Deficiency Act of 1913.

As the numbers of people with learning disabilities housed in institutions rose throughout the first half of the twentieth century, an increasing body of knowledge began to emerge that not only were the practices of institutions damaging, but that people with learning disabilities were in fact capable of much more than people had previously recognised. Thus, from the 1960s onwards, alternatives to institutional care ('care in the community') have been sought, and although it is very different in both form and ethos to the community care of the eighteenth century, it still represents a return to an earlier solution.

The role of society's attitude to people with learning disabilities in how and where care is provided seems clear. Although initially it seems that they were cared for in the community, the rise of industrialisation and the changes in attitudes and living conditions that it brought with it brought about a dark period in their care. People with learning disabilities were to be feared and contained, and as such it is not surprising that their emotional and mental health needs were neglected. At the same time as being dangerous, they were viewed as uneducable and eternally child like.

Finally, Rosen, Clark and Kivitz (1977a and 1977b) chart the development of attitudes toward people with learning disabilities from ancient Greece and Rome to the 1970s and the establishment of the principles of normalisation

(Wolfensberger, 1972). Their collection of papers reflects the mood of centuries of researchers and thinkers in this field, and shows the gradual progression from papers concentrating on how best to protect society and save public money towards the acceptance that people with learning disabilities have emotional lives and mental health needs. In this sense, the role of history can be seen as one that not only shaped individual attitudes, but also shaped services and research agendas.

#### Theoretical and clinical factors

During the first half of the twentieth century, when advances in developmental theory and psychometric testing had led to renewed interest in the field of learning disabilities (e.g. Binet and Simon, 1905, Terman, 1916; see also Shapiro, 1979), the Mental Deficiency Acts (e.g. The Mental Deficiency Acts 1913, 1927) provided for a complete separation between the two fields (mental health and learning disabilities). This had the effect of creating a spilt profession, with large numbers (the majority, in fact) of psychiatrists spending a lifetime in general adult psychiatry and never having any cause for professional concern for those with learning disabilities (Shapiro, 1979).

It is also possible to trace some of the cause for the relative neglect of this field to a general feeling of pessimism among clinicians (Berrios, 1994; Shapiro, 1979; Szymanski, 1994), encompassing theoretical, diagnostic and treatment-related issues. Traditionally, psychiatric diagnoses and clinical formulation are based to a considerable extent on the evaluation of psychological processes, emotions and affect (Syzmanski, 1994). This is mostly done through direct communication with patients, who consequently need to have both sufficient language skills to impart ideas and sufficient cognitive ability to enable some degree of conceptual thinking. Because such skills are often reduced in people with learning disabilities, many clinicians have found the process of formulation (and consequently effective treatment) difficult. For example, Reid (1972) found that while it was possible to use existing diagnostic criteria to recognise psychotic symptoms in an individual with mild learning disabilities and intact

verbal communication, it was not possible to do so using non-verbal communication alone. Deb and Weston (2000) summarise the clinical difficulties of formulation in this population as being the reduced communication abilities of the clients, a lack of appropriate assessment tools and a lack of relevant diagnostic frameworks. In addition, Moss (1999) has highlighted a number of some of the pragmatic difficulties that both people with learning disabilities and the services they seek to use face in the recognition of mental health problems. For example, he notes that people with learning disabilities are often not involved in the decision to seek help for 'symptoms'. Because of this, they may be confused as to why they have been brought before a psychologist or psychiatrist, and hence less able to help in explaining what the 'problem' is.

Moss (1999) also notes that the signs of emotional and mental health problems in this client group can be difficult to recognise, making formulation difficult. Although a number of studies have shown that the symptoms of mental health problems in people with mild and moderate learning disabilities are broadly similar to those without learning disabilities (e.g. Einfeld and Tonge, 1999), many other studies have shed some doubt on this. In addition, most would agree that the recognition of these problems in people with severe and profound learning disabilities is far more challenging. Emerson, Moss and Kiernan (1999) note that the existence of challenging behaviour is one of the most common factors clinicians take into account when attempting to diagnose mental health problems in this client group. However, they suggest that the relationship between challenging behaviour and mental health problems in people with severe and profound disabilities is far from straightforward. Although some challenging behaviour may represent a way of expressing their distress associated with the mental health problem, this need not be the case for others. Even more confusingly, there are a number of studies that question the relationship between psychiatric problems and challenging behaviour per se. For example, Rojahn, Borthwick-Duffy and Jacobson (1993), in a study of over 135,000 records of people with severe learning disabilities in the USA, found no compelling correlation between aggression, self-injury, destruction or stereotypy on the one hand and mental health problems on the other. Similarly, a largescale study of challenging behaviour in people with developmental disabilities in the UK asked respondents whether the people identified had a psychiatric disorder diagnosed by a psychiatrist (Kiernan and Qureshi, 1993). Only 89 of the 693 peopled identified (13 per cent) had such a diagnosis, but the fact that in over 59 per cent of instances respondents said that they did not know if such a diagnosis had been made, opens the possibility of failure to diagnose disorders. Finally, Syzmanski (1994) notes that many people feel uncomfortable making a diagnosis in the absence of verbal communication, and so because of this many otherwise available treatments may have been withheld.

In terms of medical treatments for mental health problems, the advent of major tranquillisers has brought mixed blessings. On the one hand, it precipitated the split between psychodynamic theory and psychiatry, as it allowed for the notion that organic (as opposed to psychodynamic) factors could be responsible for emotional disorders. This allowed psychiatrists to distance themselves from the notion of 'untreatability' (see below) and to begin to consider new causes for emotional disorders (Matson and Sevin, 1994). On the other hand, however, it also prompted an overly organic approach. As well as considering emotional distress to be largely the result of chemical imbalances (as opposed to internal cognitive processes or emotional responses to often very negative environmental conditions), much of the evidence for the efficacy of the medications being used was inconclusive (e.g. Clarke, 1997). As an example, the use of medication for self-injurious behaviour (SIB) was, until the 1980s, largely based on 'old' antipsychotics such as chlorpromazine, haloperidol and thioradizine. efficacy for these compounds is poor (Clarke, 1997), and largely based on animal models of self-injury (Clarke, 1997; Schroeder et al., 1995).

The relationship between the difficulties in establishing psychiatric diagnoses and the subsequent problems this presents in prescribing psychotropic medication in people with dual diagnosis has been explored by Kroese, Dewhurst and Holmes (2001). Kroese et al. note that, although specialised assessment tools such as the PAS-ADD (Moss et al., 1998) have been developed, the psychometric properties of them are often poor. In addition, they note that the clinical interview itself can reveal potentially confounding data.

People with learning disabilities are known to acquiesce in situations where there is a power imbalance (Sigelman et al., 1982), as is likely to be the case when a psychiatrist or psychologist interviews a person with a learning disability. Although standardised psychometric measures may be designed to ask questions in such a way as to minimise this type of response (e.g. by asking open-ended questions or multiple response questions), research has shown that the administration of interview schedules commonly involves interviewers paraphrasing both the questions and the answers (Antaki and Rapley, 1996).

Theoretical problems are also likely to have played their part in the current lack of research with people with learning disabilities and mental health problems. For example, although psychodynamic approaches are now beginning to be used for people with learning disabilities (e.g. Beail 1995, 1998; Beail and Warden 1996; Hollins and Sinason 2000; Sinason, 1992), some previous psychodynamic conceptualisations of mental illness theoretically precluded people with learning disabilities from suffering from them in the first place. For example, Syzmanski (1994) notes that one psychodynamically held view of emotional distress stated that it was caused by a failed defence mechanism against an internal conflict; problems arose when psychodynamic theorists also proposed that people with learning disabilities lacked the intellectual ability to develop such an internal conflict in the first place. On the other hand, some theorists held that all people with learning disabilities had experienced some degree of maternal rejection due to their disability, and as such all were likely to be depressed. Both ideas are borne from established theory as it pertains to adults in the normal range of intellectual functioning, and both seem to be equally unlikely. In addition, it was once proposed that people with learning disabilities could not develop depression, as their low intelligence prevented them from perceiving their deficiencies and developing low self esteem (see Matson and Sevin, 1994). Gardner (1967) proposed that one reason we may expect to find generally low levels of emotional disorders in people with learning disabilities was due to their 'difference in moral standards'. A lack of high moral standards in those with learning disabilities, he argues, translated into less guilt over failure.

Similarly, Bender (1993) has proposed that many clinicians feel a certain amount of 'therapeutic disdain' regarding the 'treatability' of people with learning disabilities and mental health problems. In charting the history of this so-called 'therapeutic disdain', Bender (1993) argues that a combination of prejudice and structural barriers have prevented people with learning disabilities from receiving psychological therapy, in much the same way as similar barriers have prevented people with psychoses, older adults, people from ethnic minorities and people with drug and alcohol problems from receiving equal services. Bender places much of the blame for the contemporary lack of research and clinical practice in the area of dual diagnosis at the door of clinical psychology. While his arguments may be seen to lack an empirical base, the points he makes are echoed in many of the reasons already advanced herein for the relative neglect of this field.

Finally, Gualtieri (1988) makes a number of interesting observations regarding the low status of learning disabilities. For example, he notes that people with learning disabilities occupy a similar status in mental health services to people with severe and enduring mental health problems; they are seen as difficult to help and somewhat of a burden. Secondly, Gualtieri (1988) suggests that, historically, psychiatrists working in the area of learning disabilities have ruthlessly applied the medical model. This has been a particular problem because, as Gualtieri notes, '...psychiatry has spent the last quarter-century pursuing the medical model with the same ardour with which mental retardation, as a field, has run away from it' (p. 174). Gualtieri therefore identifies the mismatch of ideologies between psychiatry and the wider field of mental retardation as a reason for its relative stagnation, at least as far as progress regarding the effective treatment of mental health problems is concerned.

## Do people with learning disabilities need psychological therapy?

Prior to examining this question, it is useful to clarify the meaning of some of the terminology used. In this thesis, the term 'dual diagnosis' refers to people with learning disabilities who also have mental health problems (e.g. Matson and Sevin, 1994; Nezu and Nezu, 1994). This is to be compared with the term's other main usage, which refers to people with mental health problems and drug and alcohol problems (e.g. DSM-IV, 1994). The conceptual understanding of 'psychological therapy' has been derived from Kazdin's (1988) and Corsini's (1989) definitions. This includes elements of counselling and psychotherapy in the broadest sense, and describes the following as key elements of psychological therapy:

- A formal or special interaction between two (or more) individuals, typically a 'client' and a 'counsellor' or 'therapist', where one party is specifically seeking help for ameliorating distress or dealing with a particular problem.
- The therapist or counsellor applies a set of procedures or techniques or provides a set of conditions with the aim of alleviating the distress or solving the problem, with a theoretical base underlying the therapist's activities.
- The focus of the interaction may be on cognitive, affective, attitudinal, and/or behavioural factors.
- Typically, the client describes the problems and issues related to the
  distress or concern, with the counsellor or therapist responding with
  interactions that apply techniques or set conditions for amelioration of
  the distress or concern (Strohmer and Thompson-Prout, 1994).

Thus, psychological therapy includes a wide range of interventions, encompassing different theoretical and technical viewpoints (also see Kazdin, 1988). Essentially, however, this definition excludes work such as operant

behaviour modification or behavioural consultation frameworks where the procedures or techniques are not conducted with the client in person (Strohmer and Thompson-Prout, 1994).

In this thesis, a number of different psychological therapies are differentiated. These are: Psychodynamic psychotherapy, cognitive-behavioural therapy, systemic therapy, group therapy and behaviour therapy. Psychological therapies have been categorised in this way for two principal reasons. Firstly, it was envisaged that they represent a level of distinction that most clinicians are likely to recognise, without having to claim expertise in any or all of them. Secondly, it was considered to reflect the likely variation that one might expect in those services where psychological therapy was being provided to people with learning disabilities. Admittedly, the fact that reviews have alluded to over 400 types of psychological therapy (e.g. Kazdin, 1986) makes it inevitable that these definitions do not capture the very essence of the way in which all individual psychologists and psychiatrists practise. However, it was hoped that they captured at least the spirit of the way in which the majority of psychological therapy is provided to people with learning disabilities in the NHS.

### The prevalence of mental health problems in people with learning disabilities

Considerable evidence exists to suppose that people with learning disabilities are at increased risk of developing mental health problems. However, given the complexity of issues that exists regarding recognition, classification and diagnosis, a wide variety of prevalence rates are reported. Whilst studies of the general population generally agree that around 20% of people have a psychiatric disorder (figure for lifetime prevalence) of some kind (e.g. Bland, Orn and Newsman, 1988; Dilling and Weyerer, 1984; Henderson et al., 1979), prevalence studies of psychiatric disorders in people with learning disabilities give rates varying between less than 10% and more than 80% (e.g. Borthwick-Duffy, 1994; Dosen, 1993; Gustafsson, 1997). This is likely to be the result of different definitions of learning disability and psychiatric disorder, methods of

case identification and the population studied (Caine and Hatton, 1998). Generally, higher prevalence rates (40% and above) are reported when behavioural problems are included as a psychiatric disorder or if the population studied has been selected from those already referred for psychiatric evaluation (e.g. Bouras and Drummond, 1992; Gillberg at al, 1986).

Perhaps the most accurate studies are those that use general (unselected) populations of people with learning disabilities. Reiss (1990) reported on 205 randomly selected people with learning disabilities attending community-based day programmes, finding that around 40% of the total were judged to have symptoms of a mental health problem. In a similar study, Iverson and Fox (1989) found that 36% of a sample of 165 randomly selected adults with learning disabilities had a mental health problem. Rutter, Graham and Yule (1970) studied the entire group of 8-11 year old children from one year on the Isle of Wight, using parent / teacher questionnaires and direct interviews as a means of gathering data. They found that around 35% of children with IQ's under 70 showed sufficient evidence for a diagnosable psychiatric disorder. Lund (1985), in a random sample of 302 adults with learning disabilities, found around 30% to have a mental health problem, although his research included the category of 'behaviour disorder'. Thus, the 'true' figure seems to be somewhere around 40%, or twice that of the normal population.

Limited evidence also exists regarding the prevalence of mental health problems in children with learning disabilities. Rutter, Graham and Yule (1970) note that, although children with learning disabilities constitute around 3% of all children, they account for around 15% of the total population of emotionally disturbed children. Corbett (1979) concluded that around 8% of a sample of non-institutionalised children with an IQ under 50 was diagnosable as 'depressed', although higher rates (around 15%) have been reported by Dosen (1984, 1990), Way (1983) and Benson (1985). These higher rates tend, however, to use samples based around referrals for psychiatric evaluation, and so are naturally likely to report higher levels of pathology. Matson (1988) notes that the relative neglect of this field in particular mirrors the neglect afforded to childhood psychiatric disorders generally, reflecting the fact that it is only within the last

20 years or so that children have been widely accepted as capable of suffering from diagnosable emotional disorders.

Overall, then, there is strong evidence to suggest that people with learning disabilities are at increased risk of suffering from mental health problems when compared to the general population. These studies are not, however, without their methodological weaknesses. For example, many studies include both children and adults, mix hospital and community patients or use other sampling techniques that are likely to lead to misrepresentations. For example, the much-quoted study by Reiss (1990) was completed using people from community-based day programmes. As Syzmanski (1994) points out, this is likely to lead to a certain 'top and tailing' of the sample, as neither the most adjusted nor the most disturbed are likely to appear in these settings. In addition, no standard diagnostic categories were used and the clinical evaluation was conducted 6-12 months after the initial screening interview.

## Aetiology of mental health problems in people with learning disabilities

Given the increased prevalence of mental health problems in people with learning disabilities, it is useful to consider why this might be. Clinicians now tend to use an integrative model to inform their understanding of the aetiology of mental health problems in people with learning disabilities, including organic (including genetic, chemical and sensory), behavioural, developmental and socio-cultural factors in their explanations.

#### **Organic factors**

Organic models of psychopathology emphasise physiological, biochemical and genetic factors as potential causes of mental health problems (Matson and Sevin, 1994). Chromosomal abnormalities, genetic disorders, nutritional deficiencies and other biological abnormalities all affect the development of the brain, and in

the most severe and profound cases of learning disability widespread structural brain abnormalities can be found (e.g. Crome and Stern, 1972). Because brain damage is likely to affect behaviour, personality, language and emotional response (affect) during the developmental period, many authors have cited this as one likely cause for the increased prevalence of mental health problems in people with learning disabilities. A number of researchers have found evidence for this; Rutter (1971) found mental health problems to be more common in children with learning disabilities who had neurological damage than those who had no such damage. In addition, Donaldson and Menolascino (1977) reported significant associations between neural dysfunction and childhood psychosis in people with learning disabilities. However, it seems likely that organic explanations of aetiology are only applicable to a small number of people with learning disabilities, in particular those with severe and profound disabilities. The majority of the learning disabled population have mild and moderate levels of disability, with little or no identifiable organic base (Emerson, Hatton, Bromley and Caine, 1998).

#### **Behavioural factors**

Behavioural models emphasise that the behavioural repertoire of an individual develops through the complex interactions between the individual and his or her environment. Behaviours are learned according to the principles of classical conditioning, social learning theory and operant psychology. Classical conditioning (when a neutral stimulus, present at a time of a fear response, becomes a conditioned stimulus for fear) is readily applicable to many anxiety conditions in those from the normal population, and appears equally valid when extended to people with learning disabilities (e.g. Ollendick and Ollendick, 1982). Similarly, social learning theory approaches (e.g. Bandura, 1977), which state that behaviours may develop in response to the target individual observing similar responses in another (often a care-giver) appear equally applicable to people with learning disabilities (again, see Ollendick and Ollendick, 1982).

However, the biggest research effort has been aimed at the role of operant processes in the development of mental health problems in people with learning disabilities. Using operant conditioning theory, Bijou (1966) outlined four possible explanations for the development of mental health problems in people with learning disabilities: inadequate reinforcement of pro-social behaviour, inappropriate punishment (though this is likely to be less relevant in today's climate, as a more careful approach is taken regarding punishment), reinforcement of inappropriate responses and altered stimulus-response behaviour.

#### **Developmental factors**

Developmental models may also offer a useful framework for understanding dual diagnosis. The importance of viewing a person's behaviour within the context of their developmental level is now considered essential, as behaviours considered 'pathological' for a person at a given age may be considered normal for a person who is developmentally delayed. Prevalence rates for disorders that are common in people with learning disabilities (such as depression, fears and phobias; see Matson and Barrett, 1982) may be high in comparison to people from the normal population, but usual in comparison to people with similar developmental levels. Developmental theories have also been the basis from which cognitive-behavioural approaches to the understanding of mental health problems in people with learning disabilities have developed (Matson and Sevin, 1994). For example, a number of studies have examined the cognitive variables associated with problems such as depression. Merighi, Edison and Zigler (1990) showed that people with learning disabilities had higher expectancies of failure and ridicule than those from the normal population, and that people with learning disabilities were more likely to attribute failures to internal processes and factors. Similarly, Reiss and Benson (1984) reported that many people with learning disabilities were able to articulate their feelings of ridicule, restriction and stigmatisation, and were aware of the disparity between themselves and others. It is not difficult to imagine how such thought processes could lead to feelings of depression and worthlessness.

#### Sociocultural factors

Finally, sociocultural theories need to be considered. Although today's government stresses the importance of rights, independence, choice and inclusion for people with learning disabilities (Department of Health, 2001), there can be little doubt that, overall, they form one of the most vulnerable portions of society. Modern-day recognition of the importance of sociocultural factors in the care and support of people with learning disabilities is often seen as being embodied within the principles of normalisation (Brown and Smith, 1992). Originating from Denmark's 1959 Mental Retardation Act, normalisation seeks to 'create an existence for the mentally retarded as close to normal living conditions as possible' (Bank-Mikkelson, 1980). Recognising that normal housing, education, work and living conditions are vital ingredients to the development and maintenance of self-esteem, happiness and mental health, normalisation has had a significant impact on the lives of people with learning disabilities in the UK (Brown and Smith, 1992).

In the UK, the interpretation of normalisation provided by O'Brien has become particularly influential (e.g. O'Brien, 1980). O'Brien draws out the goals, based on the principle of normalisation, that services should try and achieve. He identifies five major service accomplishments, including ensuring that service users are present in the community, ensuring that they are supported to make choices, helping service users to develop as wide a range as possible of competencies, ensuring that they are afforded respect and ensuring that they participate in community life. Often, however, changes in actual practice are scarce (e.g. Wolfensberger, 1989), and people with learning disabilities remain isolated and vulnerable.

However, no sociocultural explanation of the increased prevalence of mental health problems in people with learning disabilities would be complete without a discussion of the effect of deinstitutionalisation and relocation into the community, much of the impetus for which was derived from the principles of normalisation. Newly transferred patients are likely to experience increased exposure to fearful stimuli and failure experiences. In addition to having to contend with new routines and locations, individuals may find themselves living

without people with whom they have survived and formed friendships for many, many years (see Wing, 1997). This is likely to engender feelings of loss and abandonment. Although there are many studies showing the positive benefits of relocation into the community (e.g. Emerson and Hatton, 1994), there are also many studies demonstrating at least transient negative outcomes in terms of mental health (e.g. Sovner and Pary, 1993).

Reiss and Benson (1984) note that people with learning disabilities are often exposed to an excessive number of negative social experiences, including rejection by peers and family, infantilisation, reduced access to employment and leisure facilities and other social prejudices which contribute to poverty and feelings of dependence. It seems reasonable to assume that prolonged exposure to such negative social conditions may adversely affect mental health. In an extension to this, many authors (e.g. Matson and Sevin, 1994) have suggested that intellectual impairment may result in a reduced capacity to withstand environmental stress. Overall, people with learning disabilities are likely to encounter more difficulties in day-to-day living whilst having a reduced capacity to handle these problems. This, in turn, is more likely to lead to emotional disorders (e.g. Levine, 1985). Sovner and Parry (1993) discuss several cases where stressors such as illness or the death of a family member precipitated depressive episodes in people with learning disabilities.

Interestingly, many of the sociocultural variables that have been studied in relation to mental health in the normal population have not been studied in people with learning disabilities. Whereas the relationship between mental health in people from the normal population and factors such as socio-economic status, family background and health status is regularly reported on (e.g. Baumeister, 1988; Brown and Harris, 1978), little is made of this in relation to people with learning disabilities (Matson and Sevin, 1994). What seems clear from the literature covered above, however, is that people with learning disabilities are subject to a wide variety of potentially negative influences on their mental health. Commenting on this, Fleisher and Weiler (1990) note that it is sometimes hard to see how the combined impact of the social, emotional and

cognitive difficulties that people with learning disabilities have to face could *not* contribute to higher rates of emotional problems.

## Evidence for the effectiveness of psychological therapy for people with learning disabilities

Having considered the reasons for the relative neglect of this group in the theoretical and clinical literature, and having established the increased likelihood of people with learning disabilities suffering from mental health problems, it is finally important to review the evidence for the effectiveness of psychological therapy for individuals with dual diagnosis.

#### Interventions based on Learning Theory

Nezu and Nezu (1994) note that a number of approaches based on learning theory have been used in the treatment of mental health problems in people with learning disabilities, including strategies based on operant procedures, strategies based on respondent-conditioning principles and what they broadly call social learning approaches. Published accounts can be found for the treatment of fears and phobias, toileting problems, deficient speech skills, eating disorders, deficient self-help skills, obesity, anxiety disorders, aggression, conduct disorders, self-injurious behaviour, stress-induced vomiting and incontinence, autism, schizophrenia and major depression (Nezu and Nezu, 1994).

Nezu and Nezu (1994) provide a number of useful reflections on the state of research into the treatment of people with learning disabilities who also have mental health problems. They note, for example, that although reviews by authors such as Whitman et al. (1990) attest to the growing use of sophisticated methodologies in the assessment of treatment effectiveness, a large number of studies (particularly those using operant procedures) suffer from marked flaws. For example, they are often completed in highly controlled environments such as institutions, begging the question as to whether similar levels of contingency management would ever be possible in a community setting.

Studies investigating treatments based on respondent training (e.g. relaxation, systematic desensitisation) have been found to provide effective treatments for people with learning disabilities who have mental health problems. As well as a number of single case designs investigating treatments for problems such as poor anger control (e.g. Schloss et al. 1989), studies using group-treatment designs for problems such as phobias also exist. Peck (1977) used such a design with 20 patients split into 4 different groups to show that not only was a systematic desensitisation programme possible with people with learning disabilities who had phobias, but also that it was more effective when using a 'direct contact' (as opposed to imaginal exposure) paradigm. Similarly, McPhail and Chamove (1989) showed that relaxation training was effective in reducing aggression and verbal disruption in 6 people with learning disabilities compared to 6 control participants who were exposed to a 'story-reading condition'.

#### **Cognitive Behaviour Therapy**

Currently, one of the most widely researched psychological treatments for non learning disabled populations is Cognitive Behaviour Therapy (Roth and Fonagy 1996), a distinction which also seems to hold true when considering the treatment of psychological problems in people with learning disabilities. However, such research has yet to utilise some of the more sophisticated designs and techniques that one can find in at least some of the CBT research with non learning-disabled clients. In addition, most of what is available in the literature is language based, and so accessible only to the most able groups. This, according to Clements (1997), is borne from the fact that few therapists are willing to consider the notion that there is more to cognition than just 'thinking in words', and that until the conceptual framework surrounding CBT is broadened, the least able clients will be excluded from therapeutic interventions. Consequently, the research reported often uses single case or low 'n' designs – a fact which probably has as much to do with the number of therapists practising and clients with learning disabilities receiving CBT as it does research interest in this area.

Both Clements (1997) and Lindsay, Neilson and Lawrenson (1997) note that the small volume of literature on the treatment of anxiety in people with learning disabilities lies in stark contrast to the wealth of literature on the treatment of anxiety in those functioning within the normal range. They note three possible reasons for this. Firstly, they suggest that people with learning disabilities represent a less interesting population to clinicians - they are, in a sense, devalued. Secondly, they suggest that people with learning disabilities are often not assumed to have a stable and potent set of cognitions, making cognitive therapy inappropriate for this group. Lindsay et al. (1994) have noted, however, that this assumption is far more likely to be due to the inadequacies of measurement tools than a true reflection of the internal world of people with learning disabilities. Thirdly, Lindsay, Neilson and Lawrenson (1997) suggest that clinicians may assume that anxiety in people with learning disabilities functions in the same way as in the general population, and therefore there is no need for specifically focussed research. There are many reasons to suggest that this may not be the case, however. For example, people with learning disabilities are often brought up in relatively protected and disempowered environments, meaning that they may not have the opportunity to develop the coping skills and cognitions in relation to anxiety-provoking situations.

Lindsay, Neilson and Lawrenson (1997) note that although the literature is small and typically based on single-case designs, the outcome research that exists is encouraging. Studies evaluating the effectiveness of guided relaxation treatment (e.g. Clare et al., 1992), anxiety management training (e.g. Turk and Francis, 1990), treatment of phobia (e.g. Dixon and Gunary, 1986) and treatment of PTSD (e.g. Hudson and Pilek, 1990) have all suggested that cognitive therapies can be used in the successful treatment of mental health problems in people with learning disabilities. In addition, Lindsay, Neilson and Lawrenson (1997) present evidence that cognitive therapy for anxiety in people with learning disabilities can also be shown to be effective at 18 month follow up, although again this is only based on 2 case examples.

Very few studies have been undertaken to assess the effectiveness of psychological treatments for depression in people with learning disabilities.

Matson, Dettling and Senatore (1980) reported the effective treatment of depression in a man with mild learning disabilities using a strategy that could be broadly described as CBT. Lindsay, Howells and Pitcaithly (1993) present two case studies of individuals with mild learning disabilities referred for depression, showing that a number of CBT techniques can be adapted in order to make them more accessible to those with lower levels of intellectual functioning. Both participants completed revised versions of the Zung depression and anxiety scales (Zung 1965; Zung 1971) prior to and following treatment. In both cases, levels of depression and anxiety were reduced from clinical to non-clinical levels.

#### Psychodynamic psychotherapies

Few authors would disagree that the application of psychodynamic psychotherapies to people with learning disabilities has been poorly researched, with varying explanations. Many cite Freud's 1904 paper in which he described 'those patients who do not possess a reasonable degree of education and a fairly reliable character' as being unsuitable for psychotherapy (e.g. Bender 1993; Collins 1999) as the beginnings of what Bender (1993) describes as 'therapeutic disdain' towards people with learning disabilities. Freud was certainly not alone when considering people with learning disabilities as unsuitable for psychoanalytic psychotherapy. As recently as 1971, Tyson and Sandler disregarded the growing social and professional momentum toward normalisation and noted that 'mental deficiency is generally regarded as a contra-indication for psychoanalysis'. Indeed, Beail (1995) has noted that even within the last decade, the amount of research into the effectiveness of psychodynamic therapies for people with learning disabilities is very sparse. For example, in a review of the published accounts of treatments, Beail (1995) found only three UK-based papers covering a total of nine participants that reported outcome data, and of these the measurement was largely descriptive and anecdotal.

The reasons for this dearth of research are likely to be varied. As noted above, there is certainly a historical tendency to view psychoanalytic and psychodynamic approaches with people with learning disabilities as inappropriate; average intelligence has been seen as a pre-requisite for therapy. However, a number of early reports concerning the effectiveness of dynamic psychotherapy for people with learning disabilities indicated that it was a suitable alternative (e.g. Chidester, 1934; Chidester and Menninger, 1936), suggesting there are likely to be other reasons for its dismissal. As an example, outcome research is not, generally speaking, considered a priority by those practising psychodynamically orientated therapy. In addition, it is also important to consider the cost that fully evaluating a psychodynamic therapy service would be likely to incur; such treatments commonly last for more than a year and are often very intensive (e.g. 2-3 times a week).

In an effort to redress this imbalance, Beail (1996) reports a study of ten clients with learning disabilities referred for psychoanalytic psychotherapy for a range of problems, mainly including challenging behaviour and psychosis. The Symptom Checklist 90 –R (SCL-90-R; Derogatis, 1983) was used to assess baseline and follow-up mental health status, as was the Rosenberg Self-Esteem Scale. Analysis suggested that psychodynamic psychotherapy produced statistically significant reductions in psychological symptoms and an increase in self-esteem.

In a study looking at therapeutic outcome for people with learning disabilities, Beail (1998) assessed the effectiveness of psychoanalytic psychotherapy with 20 men. Participants were referred for both behaviour problems (mainly aggression) and offending (mainly indecent exposure), and were seen over the course of three years. Treatment varied in length from 3 to 43 months, and although no control group was used, four of the participants who did not complete treatment were assessed at 6-month follow up to provide data on those who did not receive treatment. Beail found that in all but 2 cases the intervention eliminated the problem behaviour and that this improvement was still in evidence after 6 months. This was in contrast to the four participants

from the 'control' condition, who all still displayed the problems for which they had been referred when assessed during the follow-up period.

On the basis of the very limited outcome data available, it would seem that psychoanalytic therapies could contribute to the treatment of psychological problems in people with learning disabilities. Clearly, however, there is a need for more research in this area. This seems to be important for at least two reasons. Firstly, the findings need to be corroborated and extended if clinicians are to learn more about the ways in which therapy can be applied in order for it to be equally effective for people with learning disabilities. Secondly, the lack of research in the area appears to indicate that there is still a great deal of ambivalence amongst clinicians regarding psychoanalytic therapy for people with learning disabilities. For example, Beail (1998) reports that he encountered a number of negative attitudes towards the provision of psychoanalytic psychotherapy for people with learning disabilities when attempting to seek support for some of his own work.

#### Systemic interventions

The increasing interest in the use of psychotherapeutic techniques for people with learning disabilities has also lead to the application of systemic interventions with this client group. Specifically, a number of authors have argued that this type of intervention may be particularly relevant to people with learning disabilities, whose experience of the family is often highly fragmented, disempowering and structurally different to what many consider to be a nurturing environment (e.g. Evans and Midence, 1999; Goldberg et al. 1995). As an example, both Evans and Midence (1999) and Vetere (1993) draw on the family life-cycle work of McGoldrick and Gerson (1983) to suggest that the transitional stages commonly encountered by families are very different when the family contains someone with a learning disability. When one considers the fact that over one third of adults with a learning disability live with parents who are over the age of 65 (Vetere, 1993), it is possible to see how issues relating to loss and separation assume more importance. This issue is expanded upon by

Goldberg et al. (1995), who note that the change in family life-cycle is complicated by the fact that the changes which do occur are often accompanied by a 'recapitulation of grief', meaning that the very process of change brings with it a re-experiencing of grief that has remained unresolved during previous stages of family development. Commonly, this grief is triggered by the focus on the family member's disability that stages of change provide, engendering feelings of loss of the 'perfect child' by the other members.

Acceptance of the notion that people with learning disabilities are suitable for psychotherapy, coupled with the observations made above regarding the difficulties that people with learning disabilities may face within the family suggest that it may be useful as a psychological therapy in the treatment of mental health problems. As well as being part of many complex systems, people with learning disabilities are also often dependent on others. This can create its own set of psychological problems, but might be missed if the focus of a psychologist or psychiatrist were to be on the individual rather than the system. However, little outcome research exists, and as with much of the research currently being undertaken with this population using CBT and psychodynamic psychotherapy, most of the research that does exist is process focussed. Indeed, Evans and Midence (1999) go as far as to state that the field needs '...research focussing on process rather than outcome issues...'.

#### Group approaches

Although group-based approaches are likely to employ some or all of the techniques discussed above (e.g. CBT, psychodynamic approaches, systemic approaches etc.), they are often considered to be conceptually different from their individual-therapy counterparts (e.g. Brown 1994).

Among the group approaches, both directive and nondirective techniques have been employed (Rothberg, Adams and Boyd, 1989, cited in Brown, 1994). Generally, nondirective approaches appear to have limited applicability to people with learning disabilities, as the demands of unguided introspection and negotiating the (often un-stated) rules of a non-directed group become too

burdensome. In turn, directive group therapy (e.g. CBT) appears to form the basis of the majority of the literature in this area. In contrast to other types of group therapy, the therapists in directive groups are seen as highly active and structured in their approach to the therapy (Brown, 1994). The current emphasis in the literature appears to be in social skills training, anger management training and social-sexual interaction.

It is known that people with learning disabilities have particular difficulties in dealing with social and interpersonal problems (see, for example, Ashman and Conway, 1989) and that maladaptive social behaviour can have far-ranging consequences. These vary from providing a major obstacle in community integration (Shalock, Harper and Genung, 1981) to a wide range of clinical problems, including anxiety and depression (Marx, 1988). Lee (1977) employed a group-based approach to improve the social skills of a group of people with moderate learning disabilities, emphasising personal appearance mannerisms, social interaction, perception of feelings, making friends and social responsibility. A number of baseline measurements were taken, including the Peabody Picture Vocabulary Scale-Revised, the Adaptive Behaviour Scale, peer evaluation and ward-staff evaluation. An IQ-matched control group who met once a week for non-directed activities (i.e. they were, by and large, unsupervised for an hour) was employed. Results indicated that, on each of the variables above, the experimental group showed a significantly greater mean score at the end of 10 sessions than the control group. Lee (1977) concludes that people with moderate learning disabilities can derive positive benefits from structured group social-skills training.

A similar group, designed to improve social problem solving, was designed and evaluated by Loumidis and Hill (1997). Based on a 15 session (once a week) timetable, their group included components aimed at helping participants to identify problems, generate different solutions, evaluate the likely outcome of their solutions and eventually pick and implement the most appropriate strategy. 29 people with mild and moderate learning disabilities were assigned to either a hospital-based group or a community-based group. These were compared to a control group of people not receiving any form of group therapy, as well as

baseline measurements of the participants' own problem-solving abilities. The 'trained' group showed significant improvements in a number of components of social problem solving, including 'solution effectiveness', 'number of relative means to ends' and 'number of relevant pre-action thoughts'. Loumidis and Hill (1997) conclude that people with learning disabilities can benefit in some respects from group training in social problem solving.

Group-based approaches are also commonly employed in interventions aimed at anger management. Several programmes have been developed along the lines of cognitive therapy (e.g. Benson, 1986; Foxx and McMorrow, 1983; Gardner and Cole, 1987). Common to most of these and other programmes is the provision of relaxation training, an analysis of important environmental and internal factors and an attempt to understand the key antecedent factors that commonly trigger aggression in the participant. Anger control problems are also a common source of intervention for people with learning disabilities, and whilst it is perhaps arguable that anger control is not a mental health problem, it is often conceptualised as such when considering people with learning disabilities. Benson, Rice and Miranti (1986) evaluated three different interventions for 54 clients with anger control problems, and although they found clinically significant reductions in anger in all treatment conditions (progressive relaxation, social problem solving and self-instructional coping training) after 12 weeks, no single intervention stood out as more or less effective.

## How is psychological therapy used with people with learning disabilities?

Having considered the evidence for the effectiveness of different psychological therapies with people with learning disabilities, it is also useful to review some of the evidence for how such therapies are actually utilised. Rush and Frances (2001) conducted a comprehensive survey of nearly 100 'experts' on mental health in people with learning disabilities in the USA, using their results to provide a report detailing the expert consensus on the assessment, diagnosis and

treatment of a range of psychological problems. Thy note that three types of intervention were the most highly recommended in almost every situation: applied behavioural analysis, managing the environment and client and family education. This is the case for clients of all levels of disability and with both mild and more severe psychological problems. They define applied behaviour analysis as a series of reinforcement techniques aimed at promoting functional behaviour and reducing problem behaviour, and can be thought of as analogous to 'indirect work' in the context of this study. Managing the environment describes simply changing aspects of a client's environment that might constitute a stressor or be inherently lacking (e.g. social contact), and education is defined as 'helping clients and families understand more about behavioural and psychiatric problems'. Thus, it would seem fair to suggest that these are not classifiable as talking therapies ('psychological therapies' in this research).

Of the talking therapies that were applied with people with learning disabilities, Rush and Frances (2001) found that CBT was the most readily utilised. Their data reveals that CBT was considered as an appropriate first line treatment for a number of psychological problems, including major depressive disorder, post traumatic stress disorder and obsessive-compulsive disorder. In addition, CBT was rated as a second line option for bipolar disorder, schizophrenia, generalised anxiety disorder, conduct disorder, substance abuse and adjustment disorder. Psychodynamic psychotherapy was not considered as a suitable first or second-line treatment for any of the disorders listed on axis 1 of DSM-IV, and systemic approaches were ignored completely.

## Factors affecting the provision of psychological therapy to people with learning disabilities

The purpose of the final section of this chapter is to explore five areas that are proposed to affect the provision of psychological therapy to people with learning disabilities. These are 1) the resources that a service has available, 2) the extent to which clinicians perceive psychological therapy as being effective with this

client group, 3) the extent to which they feel competent in delivering psychological therapy to this client group, 4) the level of the client's disability and finally 5) the influence of the diagnostic overshadowing bias. The proposed factors are derived both directly from the research literature and also from the author's personal experience of working in this field.

#### Service resources

People with learning disabilities do not by and large receive generic mental health services. There is evidence, however, that despite the provision of specialised services for people with learning disabilities and mental health problems, access to them is hindered by their relative paucity. If it is accepted that around 3% of the population are assumed to have a learning disability, and that people with learning disabilities are, at least on the face of it, at increased risk of developing a mental health problem, then evidence suggests that there are simply not enough services to cope with the presumed demand. For example, evidence suggests that around 25-50% of these will develop mental health problems (e.g. Gravestock 1999; Iverson and Fox, 1989; Reiss 1990), which equates to around half a million people. These are served by an indeterminate number of clinical psychologists and psychiatrists; current estimates suggest that there are around 350 clinical psychologists (not all full time) and 300 psychiatrists (Consultant and SpR level) working in learning disability services (Day, 1999). Neither figure approaches the recommended figures of one wholetime clinical psychologist and one whole-time consultant psychiatrist per 100.000 of the general population (Royal College of Psychiatrists, 1992).

Rose et al. (2001) note that the average WTE of psychologists in learning disability services is less than 1 per 250,000 of the population. This should be compared to the BPS recommended number of 4 per 250,000, and the RCP recommendation of 1 per 100,000. The cause of this shortfall is not entirely clear. Reasons are likely to include some of the perceived difficulties in working with this client group (e.g. the lack of range of applicable psychological models). Lavender and Thompson (2000) report that learning disabilities was

the preferred option for only 3 of a cohort of 78 trainees graduating from the South Thames Clinical Psychology Training Programme (cf. Thomas and Cook 1995). Many consultant psychiatrists active in the field of learning disabilities and mental health tell a similar story — that it occupies a low status within psychiatry and that posts are difficult to fill (Bouras, 2001 Personal communication; Holland, 2001, Personal communication; Holt, 2001 Personal communication). Similarly, within the profession of clinical psychology, learning disabilities has long been regarded as an unpopular speciality, and there are high vacancy rates for learning disability posts (Lavender and Thompson, 2000).

Gravestock and Bouras (1995) investigated service provision for adults with learning disabilities and mental health problems in the South Thames Regional Health Authority. They highlight an inadequate range, varying quantity and varying quality of mental health and social care provision for people with learning disabilities and mental health problems. Roy and Cumella (1993) note similar findings in a comparable study of the West Midlands Region. Both sets of authors recommend that the best way of improving care is to 'de-specialise' some of the care, and open up generic adult mental health facilities to those with learning disabilities. These comments are at odds with comments from at least some of the same authors, which advocate wholly specialised care (e.g. Bouras, 1994). These inconsistencies highlight the marked contrast between theoretical arguments of the 'ideal' service setting and the practical realities in most services.

In a recent study, Emerson (2001) suggests that 70-80% of people with learning disabilities who also have 'challenging behaviour' have no contact with psychological services. Although Emerson is describing challenging behaviour in general, at least some of this is likely to arise from underlying mental health problems. Emerson also reports that there is no significant association between having a psychological problem and receiving psychological services. In addition, he reports only limited associations between utilisation of psychological services and provision of any form of direct psychological intervention. Similar findings were reported by Oliver, Murphy and Corbett

(1987), who found that of 596 self-injuring children and adults, only 13 were receiving psychological treatment. The distinction between mental health problems and challenging behaviour is often weak in learning disabilities, and Bouras (1999) notes that psychiatric and behavioural problems are often treated as the same thing in learning disability services. The picture is further complicated by the differential expression of mental health problems in people with learning disabilities, such that many authors (e.g. Emerson, Moss and Kiernan 1999) argue that challenging behaviour is one of the main routes of expression for psychological disturbance in people with (more severe) learning disabilities.

#### Effectiveness of psychological therapy

Interest in promoting the awareness and use of empirically supported treatments is part of a broader movement that arose in the UK and was initially known as evidence based medicine (Sackett, Rosenberg and Grey, 1997). The premises of the movement are that (a) patient care can be enhanced by acquiring and using up to date and scientifically gathered knowledge and (b) it is difficult for clinicians to keep up with newly emerging information, but (c) if they do not their knowledge and clinical performance will deteriorate; consequently (d) clinicians need summaries of evidence provided by expert reviews and instruction on how to access this information during their routine practice (Chambless and Ollendick, 2001).

There are several reasons why we might assume that the ideas clinicians have in relation to the effectiveness of psychological therapy with people with learning disabilities might affect its provision. Firstly, there is a limited amount of information available regarding the general effectiveness of psychological therapy with this client group. This is particularly the case for people with more severe learning disabilities, but also applies more generally to those with moderate and mild levels of disability. Secondly, a limitation to evaluating the effectiveness of psychological therapies for people with learning disabilities is that, as in outcome research generally, certain therapeutic orientations have

received far more empirical support than others. Many authors (e.g. Emerson et al., 1998; Nezu and Nezu, 1994; Stenfert-Kroese, Dagnan and Loumidis, 1997) note that cognitive-behavioural and, above all, behavioural, approaches are by far the most widely reported in the literature. Systematic examinations of psychodynamic and systemic approaches are largely absent (with one or two notable exceptions, e.g. Beail, 1995, 1998; Beail and Warden, 1996).

However, when considering the discrepancy between different orientations in the outcome literature, a key difference between the provision of psychological therapy to people with learning disabilities and the general population emerges. When considering the discrepancy between, for example, CBT and psychodynamic outcome research, Roth and Fonagy (1996) point out that, relative to the frequency in which they are employed, approaches such as psychodynamic therapy are underrepresented in the literature. Two metaanalytic studies (Svartberg and Styles, 1991 and Crits-Cristoph's, 1992) identified around 30 research studies investigating outcome of patients receiving psychodynamic psychotherapy that, as Roth and Fonagy (1996) point out, is far less than studies that have investigated the efficacy and effectiveness of cognitive and behavioural treatments. This is not likely to be the case for people with learning disabilities; the dearth of literature regarding psychodynamic approaches and the preponderance of literature concerning behavioural approaches accurately reflects the types of psychological therapy that people with learning disabilities are likely to receive (Matson and Sevin, 1994; Nezu and Nezu, 1994).

Sackett, Rosenberg and Grey (1997) also identify the importance of the link between knowledge of treatment effectiveness and the provision of high quality services to patients. It seems likely that this may be one of the mechanisms through which the limited information available regarding the clinical effectiveness of psychological therapy with people with learning disabilities may affect the amount of provision that clinicians provide. For example, it seems likely that a clinician who has been exposed to very little information regarding the effectiveness of different types of psychological therapy for people with learning disabilities will be less likely to experiment with their

implementation than a clinician who has been exposed to many different types of information on the effectiveness of different therapeutic approaches.

#### Perceived therapeutic competence

The reliance upon segregated, specialised services for people with learning disabilities who also have mental health problems (e.g. Bouras, 1994) creates the impression of a client group with needs which exceed the skills of the type of generic training that psychologists, psychiatrists and other health professionals receive. Although most clinicians will have had at least some experience of treating mental health problems in the general adult population, they may have had little opportunity to consolidate these skills having taken up posts in learning disability services. In addition, it is conceivable that the existence of a learning disability makes clinicians feel that they are not able to use their existing skills. It was hypothesised, then, that the level of competence clinicians felt themselves to have in applying psychological therapy to people with learning disabilities would affect the amount of psychological therapy provided by that clinician.

The psychological mechanisms that underlie 'feeling competent' are likely to be complicated, and bear some discussion. Traditionally, the rubric of 'self efficacy' is used in psychological research to describe the notion of 'feeling competent', and the research literature pertaining to it is vast. Studies have investigated the role played by self-efficacy in a staggering variety of contexts, including judgement and decision-making. A needs theory of self-efficacy has been proposed (Connell and Wellborn, 1990; Deci and Ryan, 1985) which posits perceived individual competence among its basic psychological needs (along with the need for self-determination and relatedness). According to their model, individuals appraise the extent to which different contexts are able to meet each of their psychological needs. In addition, different contexts have different desired outcomes. In the context of providing a person with a learning disability psychological therapy, it is useful to think of the extent to which individual therapists see themselves as competent (or, in other words, as being high in self

efficacy) to produce desired outcomes and control or avoid undesired outcomes. In the context of a clinician working with a person with a learning disability who has mental health problems, this might mean the extent to which the clinician feels able to help the individual, whilst at the same time prevent any further deterioration in the person's condition, environment or general well being.

This theory also posits that, when an individual's basic psychological needs have been met, they will be motivated to continue to pursue activities that promote similar feelings of efficacy and competence. In other words, when a clinician is able to feel competent in their therapeutic work with a person with a learning disability, they are more likely to continue to apply psychological therapy. This process is referred to as *engagement*, and includes three components: behaviour (initiation, attention, persistence), emotion (enthusiasm, happiness, curiosity, interest) and orientation (toward the goal of understanding how to be effective). Likewise, *disaffection* (the converse of engagement) includes behaviour (avoidance, passivity, giving up), emotion (boredom, anger, anxiety, fear) and orientation (away from the goal of understanding how to be effective).

#### **Level of Disability**

Learning disability services provide care and support for clients from a wide range of abilities, often from those with borderline learning disabilities (e.g. those with IQs around 75 and who perhaps live with minimal support in the community) to those with profound disabilities who require very intensive support. In terms of assessment, diagnosis and treatment of mental health problems in this client group, this range of abilities presents clinicians with a number of complex challenges. One might predict that psychological therapy as defined in this research study (i.e. based on the notion of a one to one interaction characterised by a 'talking therapy') is generally seen as less effective as the client becomes less able to communicate verbally, introspect and apply conceptual understandings of psychological functioning. Support for this can

be found in a study by Driessen, DuMoulin, Haveman and van Os (1997) of all referrals to mental health services in a metropolitan area of the Netherlands over a 14-year period. They found that level of disability was important in the referral rate insofar as those with milder levels of disability were over four times more likely to receive psychiatric care. They conclude that this is likely to be due to a number of factors, including both the limited coping abilities of such individuals and the fact that mental health problems are more easily recognised in those with milder disabilities.

Furthermore, it seems likely that the dearth of literature relating to the treatment of people with severe disabilities using talking therapies (e.g. Nezu and Nezu, 1994) is likely to affect the judgements that clinicians working in this field make in relation to its usefulness. Commonly, people with more severe disabilities who require intervention due to a mental health problem are worked with indirectly (Caine and Hatton, 1998; Rush and Frances, 2001), and it is only recently that attempts have been made to explore the possibilities of using more interactive strategies (e.g. Beail, 1998; Sinason, 1992; Strohmer and Thompson-Prout, 1994; Waitman and Conboy-Hill, 1992). There is also evidence from the United States (Rush and Francis, 2001) to suggest that, by and large, indirect work (i.e. work with carers and family) and strategies that attempt to alter the client's environment without their explicit participation is, by and large, relied upon when attempting to help those with more severe disabilities.

Despite the fact, however, that it seems to make intuitive sense that the level of a client's disability will affect that manner in which a clinician chooses to work with them, the evidence is not incontrovertible. Rush and Frances (2001), for example, state in the results of their survey of 100 'experts' in mental health and learning disability in the USA that, when they asked clinicians about the different types of psychosocial intervention that they would use with specific target symptoms (such as anxiety, social withdrawal, sexually aggressive behaviour), there were very few differences between participants' responses for those with mild or moderate disabilities and their responses for those with severe and profound disabilities.

#### Diagnostic overshadowing

The reluctance of mental health professionals to acknowledge mental health problems in people with learning disabilities, and their tendency to overlook them as being fundamentally part of the learning disability itself has been termed 'diagnostic overshadowing' (Reiss, Levitan and Szyszko, 1982). This term refers specifically to the fact that, in the presence of a learning disability, accompanying mental health problems become less salient and significant. This can happen in either of two ways. In some instances, there is a tendency to attribute behaviour to salient factors (Bem, 1972), and since learning disability is often more salient than an accompanying mental health problem, many health professionals may overlook it (Levitan and Reiss, 1983). Secondly, clinicians may consider an emotional problem to be less significant when compared to the effects of having a learning disability, and so choose to effectively ignore it. Thus, diagnostic overshadowing may provide a partial explanation for the low levels of mental health service provision for people with learning disabilities (Levitan and Reiss, 1982; Reiss, Levitan and McNally, 1982).

Diagnostic overshadowing has been shown to exist in a number of experimental Typically, researchers ask clinicians to provide diagnoses and situations. treatment suggestions on the basis of clinical vignettes (e.g. Reiss, Levitan and Szyszko, 1982). Vignettes tend to contain brief descriptions of mental health problems (usually anxiety and depressive reactions) that concern either a person with a stated learning disability or a person with an IQ and social functioning within the normal range. All other elements of the vignettes are identical. When the results from clinicians answering questions relating to vignettes of people in the normal range are compared to the results of clinicians who answered questions relating to people with learning disabilities, the common finding is that those who received the vignette concerning the person with a learning disability are less likely to consider the person to be suffering from a mental health problem. Studies have examined this bias across a number of disciplines, finding that it is not specific to psychology and psychiatry but can also be demonstrated amongst social workers (Levitan and Reiss, 1983). More recent work, however, has questioned the robustness of the diagnostic

overshadowing bias (e.g. Spengler, Strohmer and Prout, 1990; White et al., 1995). Spengler, Strohmer and Prout (1990) have shown that the bias only appears to apply when the IQ of the client in the vignette of the person with a learning disability is placed at well below 70. For example, they showed that the effect was present when the people with learning disabilities were pronounced to have an IQ of 58, but not when they were assigned an IQ of 70 or 80.

In addition, White et al. (1995) argue that, because of this, it may only apply in the analogue conditions under which it is measured, and thus is a statistical finding as opposed to a clinical one. They suggest that the lack of an overshadowing effect in the upper and borderline levels of intelligence indicates that factors other than diagnostic errors may contribute to the difficulties services have in identifying these clients. Whether or not it occurs with real clients remains to be seen.

#### **Research Questions**

The general aim of the present study was to identify the attitudes held by clinical psychologists and psychiatrists in relation to the provision of different types of psychological therapy to people with learning disabilities. In particular, it aimed to assess the importance of the perceived effectiveness of psychological therapy with people with learning disabilities, the level of competence that clinicians feel they possess, the service resources at their disposal, the influence of the diagnostic overshadowing bias and the importance of the level of the client's disability. The specific research questions investigated were as follows:

- 1. How much psychological therapy and of what type (behaviour therapy, systemic therapy, CBT psychodynamic therapy and group work) is being offered to people with learning disabilities?
- 2. How important are service resources, individual competence and perceived effectiveness in relation to the provision of psychological therapies for people with learning disabilities?
- 3. Is the level of a client's learning disability associated with clinicians' perceptions of how effective psychological therapy is, how difficult it is to conduct, how important it is in relation to medication and how well trained clinicians feel they are to do it?
- 4. Is there is evidence of diagnostic overshadowing (i.e. do therapists rate clients described as having learning disabilities as having fewer mental health problems than those described as having IQs in the normal range) when psychologists and psychiatrists working in learning disability services reach assessment and treatment decisions?

#### **Chapter 2: Method**

## **Participants**

Participants for this study were qualified clinical psychologists and psychiatrists (Specialist Registrar [SpR] and Consultant level) working in the field of learning disabilities in the UK (England, Scotland, Wales and Northern Ireland) between July 1st and October 1st 2001. Clinicians working part time were also included. Both groups were thought to represent the key clinicians involved in the referral, assessment and treatment of people with learning disabilities who develop mental health problems.

Participants were identified in a variety of ways. Psychiatrists were identified from a central register, complied by the Royal College of Psychiatrists. This register is based on up-to-date information on the location and speciality of all psychiatrists in the UK, which is in turn derived from their policy of compulsory membership of the Royal College. All those of SpR level and Consultant level were contacted by post, and asked whether they would like to take part in the research (n=274).

No such register exists for clinical psychologists, and the process of identification of those suitable to take part was necessarily more piecemeal. Two initial strategies were employed. Firstly, secretaries of the regional Special Interest Groups were contacted by letter (appendix 1), and asked for the addresses of clinical psychologists working in learning disabilities in their region. All fifteen regional Special Interest Groups in the UK were approached. Eight were able to provide the information requested. Four did not have the information in a form readily available, and three declined to participate. Secondly, Clinical Psychology Training Courses were approached by telephone. An outline of the research was provided, and courses were asked if they would be able to provide information regarding the addresses of clinical psychologists working in learning disabilities. From a total of twenty-five courses, nineteen were able to provide this information. Three courses were unable to provide information, and three courses declined to participate.

Obviously, the latter strategy is less systematic. The true number of clinical psychologists working in the field of learning disabilities in the UK is very difficult to know with certainty. Although most geographical areas were represented during this stage of the research, it is likely that at least some potential participants were missed. Notwithstanding this, it also seems likely that the final number contacted (412) is roughly equivalent to the total population being studied. For example, Day (1998) and Emerson (2001) have both estimated that around 350 whole time equivalent (WTE) clinical psychologists work in this field. In addition, Nagel and Leiper (1998) reported identifying 280 clinical psychologists working in learning disabilities in their 1995 study.

Overall, a total of 412 clinical psychologists and 274 psychiatrists were identified. All of these were contacted with a questionnaire pack (see appendices 2-4 and below).

#### **Materials**

#### Construction of the questionnaire

The questionnaire is split into two sections:

- A section gathering basic demographic data and presenting a number of questions relating to the resources available in the respondent's service, their ratings of the effectiveness of different psychological therapies, their rating of how competent they felt in administering them and their attitudes to the role of psychological therapy with people with different levels of learning disability.
- A case vignette, aimed at assessing the existence of the diagnostic overshadowing bias.

#### Section 1: attitude survey

In order to assess the importance of perceived effectiveness of psychological therapy for people with learning disabilities, perceived competence in applying psychological therapy to this client group, service resources and the importance of the level of the client's disability, an attitude survey was constructed. This also collected information regarding demographic details (see appendix 5).

The precise relationship between attitudes and behaviour is a complex one, which exceeds the scope of this research. Herein, recognition that attitudes have some form of behavioural implication is the rationale for measuring them. The effect of attitudes amongst care staff on behaviour in learning disability services has been described by Gold (1980) in terms of an expectancy model. According to Gold, negative attitudes lead to low expectations, which in turn reduce the learning opportunities. Recognition of strengths leads to higher expectations, increased learning opportunities and increased performance.

Items were initially generated in relation to the hypotheses listed to reflect the issues of service resources, effectiveness, competence and the level of disability. An equal number of items were generated for perceived effectiveness of therapy and perceived competence in delivering therapy, following guidelines laid out by Barker, Pistrang and Elliot (1994). Participants were asked to indicate how effective they considered a range of different psychological therapies to be (including behaviour therapy, CBT, psychodynamic therapy, systemic therapy, group therapy and indirect work), and to indicate how competent they felt in administering them. In order to assess the importance of the level of the client's disability in the decision making process of participants, a series of 12 questions was presented asking respondents to indicate their agreement with statements relating to the role of psychological therapy with people with mild, moderate and severe learning disabilities. A five-point Likert-type scale was adopted throughout the questionnaire, with identical anchor-points throughout ('not at all' to 'yes, definitely'). A five-point scale was adopted due to the fact that, although reliability generally increases with more scale points (Nunnally, 1978), there is evidence to suggest that returns diminish significantly after five points (e.g. Lissitz and Green, 1975).

Those items relating to service resources, perceived effectiveness of psychological therapy and perceived individual competence were combined to form composite measures. As such, they can be thought of as *subscales*. The precise components of these scales is summarised below in table 1, along with their respective internal consistency coefficients.

Essential demographic questions were located throughout the questionnaire, in order to delineate the different sections and to gain information relating to the resources that were available to each of the participants. Respondents were asked to indicate the range and extent of support they had from different kinds of colleagues in their service.

Table1: Items included in the 3 subscales

| Subscale          | Items (item number in brackets, see appendix 5)  | Cronbach's Alpha |
|-------------------|--|------------------|
| Service resources | WTE of post (3) No. of psychiatrists (6), psychologists (7), Counsellors (8) and clinical psychology trainees (9)        | 0.67             |
| Effectiveness*    | Perceived effectiveness of CBT (12), psychodynamic therapy (14), group therapy (16) and systemic therapy (18)            | 0.69             |
| Competence*       | Perceived competence in administering CBT (23), psychodynamic therapy (24), group therapy (25) and systemic therapy (26) | 0.71             |

<sup>\*</sup> Although included in the questionnaire, ratings for behaviour therapy and indirect work were omitted from these scales as they were intended to reflect a construct akin to 'talking therapy'.

#### Section 2: case vignettes

Following Reiss, Levitan and Szyszko (1982), two different case vignettes were generated in order to assess the importance of the diagnostic overshadowing bias

in the provision of psychological therapy to people with learning disabilities and mental health problems (see appendix 5). Each case vignette described a hypothetical case of a person with emotional problems. Each vignette differed only in terms of the information provided regarding the patient's IQ and probable level of social functioning, one being the description of a person with a learning disability and one being the description of a person with an IQ and social functioning within the normal range. All other information was identical between the two vignettes. Participants were then asked to rate the likelihood that the individuals described in the vignettes were suffering from any of five psychological problems, rated on a seven-point scale (following Reiss, Levitan and Szyszko, 1982). A number of authors (e.g. Levitan and Reiss, 1983; Reiss, Levitan and Szyszko, 1982; Spengler, Strohmer and Thompson-Prout, 1995) have shown that this design of study can demonstrate the so-called diagnostic overshadowing bias, such that those receiving the vignette of the person with an IQ in the normal range are more likely to 'diagnose' the presence of mental health problems than those with the vignettes describing people with learning disabilities.

Only one published study has examined the diagnostic overshadowing bias in the UK (Sayal and Bernard, 1998), and this failed to find any such effect. However, Sayal and Bernard's study used a vignette that alluded to the presence of psychosis, rather than simply emotional problems (cf. Levitan and Reiss, 1983; Reiss, Levitan and Szyszko, 1982; Spengler, Strohmer and Thompson-Prout, 1995). They also used trainees as opposed to qualified clinicians, and only a small sample was used. Interestingly, however, although they found no evidence of the diagnostic overshadowing bias, they did report that participants in their study were less likely to recommend any form of treatment to those with learning disabilities. In order to further investigate this finding in the current study, participants were also asked to comment on the applicability of psychological therapy for the individual, the appropriateness of medication, of a Mental Health Act assessment and of an admission to a psychiatric ward. These were chosen as they were thought to reflect the range of possible interventions a psychologist or psychiatrist might consider in the event of an underlying mental health problem. These were also assessed using a seven-point scale, following Levitan and Reiss (1983) and Reiss, Levitan and Szyszko, (1982).

#### **Pilot study**

In order to assess the face validity of the questionnaire, a small pilot study was undertaken. Five academic psychologists working in the field of learning disabilities were forwarded a draft of the questionnaire. Academic psychologists were selected in order to maximise the potential sample of clinical psychologists in the main sample. Each participant was asked to comment on:

- The length of the questionnaire
- The relevance of the items in the questionnaire
- The ease with which they understood the purpose of the questionnaire

Participants were also asked to give general comments regarding the questionnaire specifically and the study in general. All five participants returned their comments to the author. Suggestions included:

- Offering a definition of 'psychological therapy'
- Shortening the questionnaire to only 2 pages
- Clarifying the meaning of a number of items
- Including a question on length of time in current post

All of the recommended changes were incorporated into the final version of the questionnaire (appendix 5).

#### **Procedure**

Each participant was sent a questionnaire pack, containing the following items:

- A consent form (appendix 2)
- An information letter (appendix 3)
- A questionnaire and vignette (appendix 5)

Two versions of the questionnaire were sent out. Participants were randomly allocated to one of two conditions. Half of the participants received a questionnaire containing the attitude survey and a case vignette of a person with an IQ falling within the normal range. The other half of the participants received a questionnaire containing the same attitude survey but with a vignette of a person whose IQ fell within the learning disability range (i.e. below 70). Apart from the differences between the vignettes, all questionnaires were identical.

In some cases, one addressee had agreed to act as a central point for a group of psychologists. This was normally only the case where an address could only be located for the secretary of a Special Interest Group, rather than for its individual members. In such cases, the right number of questionnaires was sent to the organising psychologist, who distributed them accordingly. Each questionnaire was already placed in an envelope by the author, in order that roughly equal numbers of each version of the questionnaire were distributed and that this process was 'blind' to the organising psychologist.

Addressed reply envelopes were provided to increase the response rate.

## Follow-up interviews

Participants were asked to indicate on their questionnaires whether they would agree to take part in a brief follow-up telephone interview. This was included as a way of expanding on some of the issues that arose from the analysis of the questionnaire data. Five participants were randomly selected from those that agreed. The information from three of these participants is presented in the discussion section.

### **Ethical approval**

The research was peer reviewed by staff at the sub-department of clinical health psychology, University College London. Ethical approval was sought from the

University College London Clinical Research Ethics Committee (see appendix 4). Permission to use the addresses of psychiatrists working in the field of learning disabilities throughout the UK was granted by the Research Committee of the Royal College of Psychiatrists. All participants who returned questionnaires signed a consent form giving permission for the information contained within it to be used anonymously for the purposes of research (see appendix2).

### **Chapter 3: Results**

## Characteristics of the sample

223 people returned completed questionnaires, giving an overall response rate of 32%. Of these, 133 were psychologists (32% response rate) and 90 were psychiatrists (32% response rate).

## **Data screening**

In order to prepare the data for further analyses, a number of screening procedures were adopted:

- Checks were made for normality on all key variables; although a number
  of variables were mildly skewed or demonstrated varying degrees of
  kurtosis, all were deemed to be within the range of acceptability for
  normality. Consequently, none were transformed.
- Checks were made for outliers by computing z-scores of the group means for each of the key variables. Two respondents (one psychologist and one psychiatrist) were found to have a number of z-scores over 3, and thus were deleted from the analyses.

Analyses were therefore conducted on 221 participants (132 psychologists and 89 psychiatrists). 44.8% of the sample was male, and 52.2% were female.

## **Demographic features**

The key demographic features of the sample are presented in table 2 below, along with an analysis of any mean differences in this data between psychologists and psychiatrists.

Table 2: Demographic features of sample

|                               | Mean (SD)<br>psychologists | Mean (SD)<br>psychiatrists | Df  | t    | Sig   |
|-------------------------------|----------------------------|----------------------------|-----|------|-------|
| Whole time equivalent of post | .89 (.2)                   | .97 (.1)                   | 219 | 3.53 | .0001 |
| Years since qualification     | 12.95 (9)                  | 15.30 (8)                  | 219 | 2.08 | .046  |
| Years in current service      | 6.56 (5)                   | 4.51 (4)                   | 219 | 2.99 | .003  |

Table 2 shows that significant differences exist between psychologists and psychiatrists. Psychiatrists appeared more likely to be full time than part time (mean WTE was nearly 1) and to have been qualified for longer. Despite this, it appeared that psychologists remained in their posts longer.

## Type and amount of therapy provided

Participants were asked to indicate which types of psychological therapy they used and how many hours they spent per week providing these (see research question 1, p. 36). Their responses are summarised below in table 3. The table shows CBT and behaviour therapy to be the types of therapy most likely to be delivered (at least as far as psychologists are concerned), but shows indirect work to be the clear leader in terms of the type of intervention most readily called upon.

Table 3: Summary of therapies provided to people with learning disabilities

| Therapy                  | % psychologists using: | Mean (SD)<br>hours per<br>week | %<br>psychiatrists<br>using: | Mean (SD)<br>hours per<br>week |
|--------------------------|------------------------|--------------------------------|------------------------------|--------------------------------|
| Behaviour<br>therapy     | 65%                    | 4.96 (4.7)                     | 33%                          | 1.02 (1.88)                    |
| Cognitive<br>therapy/CBT | 69%                    | 4.41 (4.8)                     | 29%                          | .44 (.87)                      |
| Psychodynamic therapy    | 52%                    | 1.19 (1.9)                     | 46%                          | .70 (1.27)                     |
| Group therapy            | 72%                    | .9 (1.4)                       | 27%                          | 0.4 (.34)                      |
| Systemic therapy         | 76%                    | 3.09 (3.8)                     | 22%                          | .63 (1.51)                     |
| Indirect work            | 97%                    | ~                              | 98%                          | -                              |

<sup>&#</sup>x27;- 'Respondents were not asked to indicate how much indirect work they undertook per week, as responses from the pilot study indicated that this figure would be too difficult to calculate.

## Service resources, effectiveness and competence

#### Service resources

Data were collected regarding the resources available to learning disability services in the UK (see research question 2, p. 36). These are summarised in table 4, below.

Table 4: Mean resources available (as rated by respondents) to learning disability services in the UK

|                                 | Mean (SD) | Range  |
|---------------------------------|-----------|--------|
| No. of psychologists in service | 2.8 (2.5) | 0 – 15 |
| No. of psychiatrists in service | 3.2 (2.8) | 0 – 12 |
| No. of counsellors in service   | .78 (1.3) | 0 – 10 |
| No. of trainees in service      | 1.9 (1.7) | 0 - 10 |

Table 4 shows the diversity that exists in terms of the sizes of departments providing services to people with learning disabilities who have mental health problems. For example, an examination of the figures for the number of psychologists shows that, although the average number per service is around 3, some services have as few as none and some services have as many as 15.

#### **Competence and effectiveness**

Respondents were asked how effective they considered a variety of different psychological therapies to be in alleviating psychological distress, and how competent they felt in administering them (research question 2, p. 36). Because ratings of each therapy are measured on comparable metrics, and because differences in mean rating between therapies is of interest here, a repeated measures ANOVA using the multivariate approach was used. Therapy type was treated as a within-subjects factor, while role (psychologist versus psychiatrist) was treated as a between subjects factor. This analysis allows for tests of overall difference in mean between different therapies, overall mean differences between psychologists and psychiatrists and differences in the profile of means across therapies between psychologists and psychiatrists (therapy x role interaction). Role was included as a between-subjects factor to allow for the possibility that psychologists and psychiatrists, due to their different training experiences in the field of psychological therapy and the differences in

expectations of their role within a team, would have different conceptions of their levels of competence and effectiveness. Individual cell means are summarised below, in table 5.

In terms of effectiveness, the ANOVA showed a significant main effect for type of therapy (F (5, 215) = 48.56, p=<.0001), but not for role (F (1,219) = .002, ns). The interaction between type of therapy and role was, however, significant (F (5, 215) = 4.56, p=.001). Simple effects and pairwise comparisons were used to explore the main effect and interaction in more detail. In order to control for the inflated type-1 error rate associated with the high number of comparisons, a correction was used (Sidak correction).

Table 5: Mean effectiveness and competence ratings for different psychological therapies

|                       | · · · · · · · · · · · · · · · · · · · |                                  |
|-----------------------|---------------------------------------|----------------------------------|
| Therapy               | Mean rating psychologist (SD)         | Mean rating<br>psychiatrist (SD) |
| Effectiveness         |                                       |                                  |
| Behaviour therapy     | 3.69 (.9)                             | 3.62 (.83)                       |
| CBT                   | 3.92 (.84)                            | 3.99 (.61)                       |
| Psychodynamic therapy | 2.95 (1.1)                            | 3.15 (1.19)                      |
| Group therapy         | 3.45 (.79)                            | 3.55 (.88)                       |
| Systemic therapy      | 3.77 (.77)                            | 3.37 (.90)*                      |
| Indirect work         | 4.01 (.73)                            | 4.08 (.64)                       |
| Competence            |                                       |                                  |
| Behaviour therapy     | 4.16 (.81)                            | 3.07 (1.08)*                     |
| CBT                   | 3.75 (.97)                            | 2.80 (1.12)*                     |
| Psychodynamic therapy | 2.19 (1.35)                           | 2.55 (1.30)                      |
| Group therapy         | 2.97 (1.12)                           | 2.57 (1.10)*                     |
| Systemic therapy      | 3.02 (1.13)                           | 2.37 (1.25)*                     |

<sup>1=</sup> strongly disagree, 5=strongly agree)

For clarity, the significant pairwise differences between psychologists and psychiatrists are shown on table 5 (with a \*, signifying p=<.05). Here, it can be seen that only systemic therapy showed any differences between psychologists and psychiatrists in terms of effectiveness ratings, with psychologists rating it as significantly more effective. Further analysis using pairwise comparisons revealed that, overall, psychologists rated CBT as the most effective of the talking therapies, rating it as significantly more effective than psychodynamic therapy (p=<.05) and group therapy (p=<.05). Psychodynamic therapy was, in

<sup>\* =</sup> sig difference (p=<.05) using pairwise comparisons within ANOVA to investigate effect of role for each therapy

fact, rated as significantly less effective than all of the other therapies considered, including indirect work. Psychiatrists showed a similar pattern, although they appeared to rate CBT as being generally more effective than their psychologist counterparts (as well as rating it as significantly more effective than psychodynamic therapy and group therapy, they also rated it as significantly more effective than behaviour therapy (p=<.05) and systemic therapy (p=<.05).

In terms of perceived individual competence, a main effect was observed for type of therapy (F (4, 216) = 37.32, p=<.0001), role (F (1, 219) = 33.57, p = <.0001) and the interaction effect (F (4, 216) = 10.39, p = <.0001). A number of significant differences existed between psychologists and psychiatrists in their ratings of competence, such that psychologists generally rated themselves as significantly more competent than psychiatrists. The one type of therapy where this was not apparent was psychodynamic therapy (see table 5). Further analysis using pairwise comparisons of the competence ratings showed that psychologists rated themselves as most competent in behaviour therapy, rating themselves as significantly more competent in this than any of the other therapies (at p= <.05 level). CBT was also highly rated, with psychologists rating themselves as more competent in this than all of the therapies except behaviour therapy (p=<.05). Psychologists rated themselves as least competent in psychodynamic therapy, which they rated as being significantly less competent in than all of the other therapies considered (all at p=<.05 level). Psychiatrists showed a slightly different pattern of competence, rating only behaviour therapy as a domain of competence with any consistency (seeing themselves as more competent in this than psychodynamic therapy, group therapy and systemic therapy; again all at (p=<.05 level).

## The influence of perceived effectiveness, individual competence and service resources on provision of psychological therapy

The importance of perceived effectiveness, perceived competence and service resources can also be assessed by examining their influence on the provision of psychological therapy (see research question 2, p. 36).

In order to assess the influence of effectiveness and competence, the ratings for each participant on the effectiveness of each of the psychological therapies (with the exception of behavioural therapy and indirect work) considered in the questionnaire were collapsed into an overall 'effectiveness' variable. Similarly, the competence ratings for each of the individual psychological therapies (again, with the exception of behavioural therapy and indirect work, which were excluded as they were not considered to be prototypical 'talking therapies') were collapsed into an overall 'competence' variable. A 'service resources' variable was calculated by summing the WTE of the participant's post and the number of other psychologists, the number of psychiatrists and the number of counsellors and clinical psychology trainees (see table 1).

The effects of service resources, effectiveness and competence on the provision of psychological therapy were assessed using a multiple regression. The dependent variable (DV) represented the total number of hours each respondent said they spent applying psychological therapy (CBT, psychodynamic therapy, group therapy and systemic therapy; items 28-31: see appendix 5) each week. The overall regression was found to be significant ( $R^2 = .11$ , F (3,217) = 8.57; p=<.0001). A summary of the regression model and the relative contribution of the different independent variables (IVs) are provided below in table 6. Squared partial correlations (SPCs) are included as an expression of the percentage of unique variance contributed to the regression by each predictor variable.

Table 6: Summary of regression model for effect of competence, effectiveness and service resources on provision of therapy

|               | Standardised B | T     | Sig   | SPC  |
|---------------|----------------|-------|-------|------|
| Effectiveness | 036            | 537   | .592  | <01  |
| Competence    | .314           | 4.67  | .0001 | .09  |
| Resources     | 123            | -1.19 | .057  | .016 |

 $R^2 = .11, F(3, 217) = 8.57, p=<.0001$ 

The regression summary in table 6 shows perceived competence to be the only significant independent contributor to the variance associated with the number of hours a clinician provides psychological therapy for. Although statistically significant, however, the unique contribution of perceived individual competence to the provision of psychological therapy is relatively small, accounting for 9% of the variance in the DV. It is of course possible that there are differences in the factors that influence the provision of psychological therapy for psychologists and for psychiatrists. In order to investigate this, the regression was re-run in the same way but on the separate samples. The results of the analysis for psychologists is summarised below in table 7. The regression analysis for the psychiatrists was not significant ( $R^2 = .023$ , R = .67, R = .57).

Table 7: Summary of regression model for effect of competence, effectiveness and service resources on psychologists only

| 4.20.         | Standardised B | T     | Sig  | SPC  |
|---------------|----------------|-------|------|------|
| Effectiveness | .001           | .006  | .995 | <.01 |
| Competence    | .237           | 2.68  | .008 | .05  |
| Resources     | 159            | -1.87 | .066 | <.01 |

 $R^2 = .08$ , F (3, 128) = 3.41, p=.02

The analysis for the psychologists (table 7) revealed a similar pattern to that showed in the overall regression analysis, demonstrating the importance of the

role of perceived individual competence when providing psychological therapy to this client group.

Whereas the regression analyses summarised above were used to assess the importance of service resources, effectiveness and competence in the provision of psychological therapy taken as a whole (i.e. by including all types of psychological therapy listed in the questionnaire together), it is also possible to begin to assess the contribution of these variables on the provision of different types of psychological therapy.

Table 8: Summary of regression models for effect of competence, effectiveness and service resources on the provision of CBT, psychodynamic, systemic and group therapy

|   | Standardised B | $\overline{T}$ | Sig   | SPC  |
|---|----------------|----------------|-------|------|
| <b>CBT</b> $(R^2 = .22, F(3, 217) = 19.84, p = <.0001)$             |                |                |       |      |
| Effectiveness   | .008           | .13            | .90   | <.01 |
| Competence  | .46            | 7.28           | .0001 | .19  |
| Resources   | 05             | 89             | .371  | .04  |
| <b>Psychodynamic</b> $(R^2 = .39, F(3, 217) = 45.33, p = < .0001)$  |                |                |       |      |
| Effectiveness   | .14            | 2.16           | .03   | .02  |
| Competence  | .53            | 8.36           | .0001 | .24  |
| Resources   | .049           | .91            | .36   | <.01 |
| <b>Systemic</b> ( $R^2 = .30$ , $F(3, 217) = 31.2$ , $p = <.0001$ ) | İ              |                |       |      |
| Effectiveness   | .09            | 1.3            | .17   | <.01 |
| Competence  | .501           | 7.81           | .0001 | .22  |
| Resources   | .133           | 2.32           | .02   | .02  |
| <b>Group</b> $(R^2 = .14, F(3, 217) = 11.48, p = <.0001)$           |                |                |       |      |
| Effectiveness   | .05            | .704           | .482  | <.01 |
| Competence  | .36            | 5.39           | .0001 | .09  |
| Resources   | .02            | .326           | .745  | <.01 |

Table 8 summarises the regression analysis for each of the 4 psychological therapies considered. As well as showing each regression to be significant, the table also clearly demonstrates the consistent importance of perceived competence in administering psychological therapy.

However, it was also recognised that, in some cases, there may be differences in the importance afforded to competence, effectiveness and service resources between the two professions, perhaps because of different levels of training, ways of working and expectations placed upon them. Consequently, the data summarised in table 5 were used to guide any further analyses that may be required. In instances where psychologists and psychiatrists appeared to agree on the effectiveness of a particular psychological therapy or their competence in administering it, no further regression analyses were conducted. In cases where significant differences existed between the professions (see table 5), additional regression analyses were conducted.

Due to differences noted between psychologists and psychiatrists in their competence in administering CBT (see table 5), regressions were also run for the two professions separately. Neither regression was significant. Given that the ratings of effectiveness and competence for psychodynamic therapy were highly similar between the professions (table 5), no additional regression analyses were conducted. Due to differences noted between psychologists and psychiatrists in their ratings of their competence in group therapy (although not in their ratings of effectiveness) regressions were also run for the two professions separately. These showed that although psychologists counted competence as more important in their decision of how much therapy to provide (SPC= 6%), psychiatrists were more reliant on their estimates of its effectiveness (SPC=8%). Differences in the ratings between psychologists and psychiatrists on both the effectiveness and their competence in systemic therapy suggested separate analyses might reveal important differences (see table 5). As in the case of the whole group, psychologists only used their ratings of their competence in systemic therapy and the amount of service resources they had at their disposal in their decisions about how much therapy of this kind they provided. Psychiatrists, however, also included effectiveness as an important factor (SPC = 12%).

## The influence of level of disability

The influence of the level of the client's disability is explored in detail in table 9, which summarises the responses of participants to the questions relating to effectiveness, the importance of medication, the level of training that respondents felt they had in administering psychological therapy and the level of difficulty that they associated with carrying out psychological therapy (see research question 3, p. 36).

Table 9: The effect of level of disability

|                          | Mean rating Psychologists (SD) | Mean rating<br>Psychiatrists (SD) |
|--------------------------|--------------------------------|-----------------------------------|
| Effectiveness            | T sychologists (SD)            | rsychiairisis (SD)                |
| Mild LD                  | 4.42 (.83)                     | 4.54 (.58)                        |
| Moderate LD              | 3.64 (1.02)                    | 3.61 (.78)                        |
| Severe LD                | 2.58 (1.27)                    | 2.56 (1.03)                       |
| Importance of medication |                                | ,                                 |
| Mild LD                  | 1.28 (.57)                     | 1.91 (.98)*                       |
| Moderate LD              | 1.44 (.76)                     | 2.01 (.92)*                       |
| Severe LD                | 1.59 (.89)                     | 2.12 (1.05)*                      |
| Difficulty               |                                |                                   |
| Mild LD                  | 3.11 (1.41)                    | 3.16 (1.35)                       |
| Moderate LD              | 3.64 (1.19)                    | 3.70 (1.1)                        |
| Severe LD                | 4.26 (1.17)                    | 4.26 (1.08)                       |
| Level of training        |                                |                                   |
| Mild LD                  | 4.10 (.84)                     | 3.22 (1.17)*                      |
| Moderate LD              | 3.67 (1.14)                    | 2.75 (1.22)*                      |
| Severe LD                | 2.87 (2.35)                    | 2.33 (1.24)*                      |

<sup>(1=</sup> strongly disagree, 5=strongly agree). \*= sig difference (p=<.05) using pairwise comparisons within ANOVA

Again, because ratings of each of the domains under consideration were measured on comparable metrics, and because differences in mean rating between the level of disability (mild, moderate or severe) is of interest here, a series of repeated measures ANOVAs using the multivariate approach were used. Each domain (effectiveness, importance of medication, difficulty of undertaking therapy and level of training) was treated as a within-subjects factor, while role (psychologist versus psychiatrist) was treated as a between subjects factor. Again, this allowed for the consideration of the likely differences in the training in psychological therapy and role expectations between the two professions. The effects were examined in more detail using pairwise comparisons (see means summarised in table 9). The sidak correction was used due to the large number of contrasts. Where possible, these have been shown on table 9, and significant differences are denoted by a \* symbol.

A significant main effect was noted for the effectiveness of psychological therapy on level of disability (F (2, 218) = 262.69, p=<.0001). No significant interaction effect (effectiveness x role) was noted. Analysis using pairwise comparisons revealed that respondents felt that psychological therapy became less effective as the level of disability increased (p=<.05). No significant differences were noted between psychologists and psychiatrists in this respect.

A significant main effect was also noted for the effect of medication (F (2, 218) =21.56, p=<.0001). The interaction between effectiveness and role was not significant. Pairwise comparisons revealed that both professions considered medication to assume an increasing importance in the treatment of mental health problems as the level of disability increased (significant at .05 level), although psychiatrists rated medication as significantly more useful than psychologists across the three levels of disability. Despite this, the mean ratings of both professions were low, indicating that neither invested particular importance in the sole importance of medication.

The main effect for the difficulty of undertaking psychological therapy with this client group was also significant (F (2, 218) = 86.15, p=<.0001). The interaction between difficulty and role was not significant. Pairwise comparisons showed that psychological therapy was equally rated by both professions as becoming increasingly difficult as the level of disability increased (p=<.05).

Finally, a significant main effect was noted for the level of training that clinicians felt they had received in providing psychological therapy to people with different levels of disability (F (2, 218) = 53.87, p=<.0001). There was no significant interaction between level of training and role. Although both groups of profession felt that the level of training they had received in the administration of psychological therapy significantly decreased as the level of disability increased (again, significant at p=<.05 level), psychologists rated themselves as significantly more well trained across all three levels of disability than psychiatrists (p=<.05; see table 9).

## The influence of the diagnostic overshadowing bias

Because of the nature of the way in which diagnostic overshadowing is assessed (at least in this study), its contribution to whether or not psychological therapy is provided has to be measured in an essentially indirect way. This is achieved by assessing whether or not the bias is influencing the decisions of the participants in this study, and then using this information as a basis for estimating its likely impact on the provision of therapy (see research question 4, p. 36)

Diagnostic overshadowing refers to a hypothesised bias that clinicians bring to bear in the recognition (i.e. diagnosis) of mental health problems in people with learning disabilities. This was assessed by comparing the extent to which clinicians attributed a set of psychological problems to a person described in a vignette to have a learning disability (received by one half of the sample) with a person described in a vignette described as having an IQ in the normal range (received by the remaining half of the sample).

In order to investigate this, a MANOVA was used. Type of vignette (learning disability and normal range) and role (psychologist or psychiatrist) were treated as fixed (between groups) factors, and the ratings on each of the 9 questions asked in conjunction with the vignette as the dependent variables. Subsequently, simple effects and pairwise comparisons were used to explore the main effects and the interaction. Omnibus F-tests showed significant overall effects for type of vignette (F (9, 209) = 10.26, p=<.0001) and role (F (9, 209) =

10.52, p=<.0001). In addition, the interaction of role and type of vignette was significant (F (9, 209) = 2.07, p=.034). Individual cell means are presented below in table 10.

Table 10: The effect of type of vignette on diagnosis

| Diagnosis      | Mean (SD) Normal | Mean (SD) LD |
|----------------|------------------|--------------|
| Schizophrenia  | 2.97 (1.26)      | 2.02 (.88)*  |
| Drug Problems  | 3.43 (1.15)      | 2.41 (.89)*  |
| Depression     | 5.38 (1.14)      | 5.21 (1.27)  |
| Anxiety        | 4.05 (1.32)      | 4.04 (1.30)  |
| Bullying       | 4.66 (1.51)      | 4.44 (1.19)  |
| Admission      | 2.65 (1.27)      | 2.27 (1.29)* |
| MHA Assessment | 2.82 (1.78)      | 2.26 (1.23)* |
| Medication     | 4.35 (1.32)      | 3.69 (1.41)* |
| Therapy        | 5.39 (1.13)      | 5.74 (1.14)* |

Scale: 1= not at all, 7 = yes, definitely

Results indicate that diagnostic overshadowing does appear to be present. Follow up analysis of the means presented in table 10 using pairwise comparisons analysis (with Sidak correction) showed significant differences in the predicted direction for both schizophrenia (p=<.05) and drug-problems (p=<.05). Differences were also observed in the type of treatment that each group (learning disabled or normal range) were recommended; those with a learning disability were less likely to be considered for an admission to a psychiatric hospital (p=<.05), for a mental health act assessment or for medication (p=<.05). They were, however, significantly more likely to be recommended as candidates for psychological therapy (p=<.05).

<sup>\* =</sup> sig difference (p=<.05) using pairwise comparisons within MANOVA to investigate main effect of type of vignette

Table 11: The effect of role on diagnosis

| Diagnosis      | Mean (SD) Psychologist | Mean (SD) Psychiatrist |
|----------------|------------------------|------------------------|
| Schizophrenia  | 2.38 (1.18)            | 2.69 (1.17)            |
| Drug Problems  | 2.85 (1.16)            | 3.02 (1.13)            |
| Depression     | 5.05 (1.24)            | 5.67 (1.04)*           |
| Anxiety        | 4.0 (1.38)             | 4.11 (1.24)            |
| Bullying       | 4.74 (1.04)            | 4.29 (1.20)            |
| Admission      | 2.03 (1.03)            | 3.08 (1.40)*           |
| MHA Assessment | 2.1 (1.15)             | 3.17 (1.84)*           |
| Medication     | 3.64 (1.34)            | 4.61 (1.30)*           |
| Therapy        | 5.82 (1.11)            | 5.19 (1.10)*           |

Scale: 1= not at all, 7 = yes, definitely

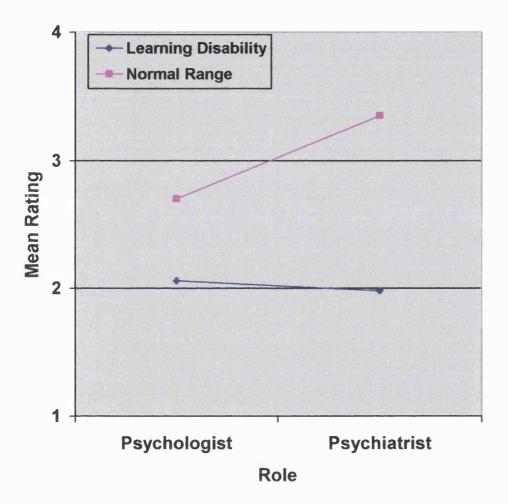
Although some existing studies have considered different occupations in relation to the diagnostic overshadowing bias (e.g. social workers and teachers), no study to date has examined the differences *between* occupations. Table 11 above shows the means from the ratings of psychologists and psychiatrists on each of the 9 categories offered by the questionnaire. Again, the differences between the means were assessed using a pairwise comparisons approach. Psychiatrists were significantly more likely to diagnose depression than psychologists (p=<.05), and significantly more likely to consider admission, a mental health act assessment and the use of medication than psychologists (p=<.05). Psychologists were significantly more likely to consider psychological therapy to be appropriate (p=<.05).

However, the presence of the interaction effect between role and type of vignette suggests that neither role nor type of vignette alone can adequately explain the observed differences in the ratings of the appropriateness of the various diagnoses. Univariate factorial ANOVAs revealed the source of the interaction to be due to differences for ratings of schizophrenia, drug problems and the

<sup>\* =</sup> sig difference (p=<.05) using pairwise comparisons within MANOVA to investigate main effect of role

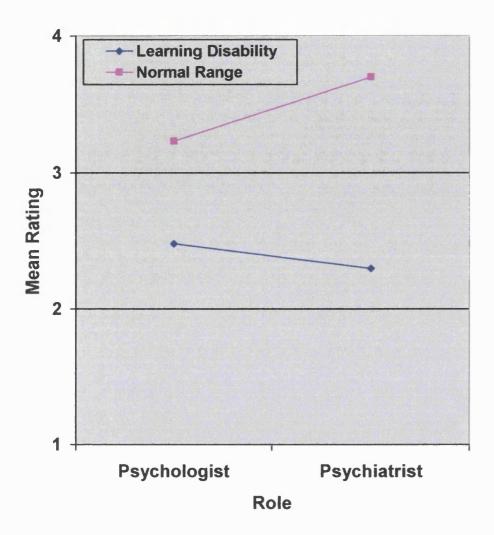
requirement of a Mental Health Act (MHA) assessment. In order to better understand the interaction effects for these three variables, line graphs were constructed from the means (figures 1 - 3 below).

Figure 1: Ratings of schizophrenia by role and type of vignette



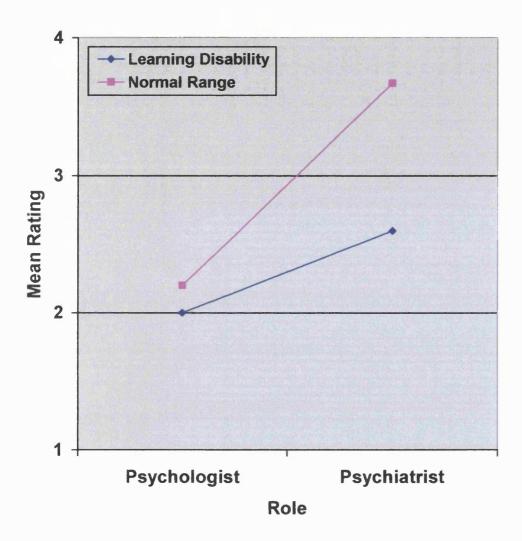
Figures 1-3 show the interaction effects in more detail. For example, figure 1 shows that, for ratings of schizophrenia, the difference in mean ratings between type of vignette is greater for psychiatrists than it is for psychologists, and that this is likely to be the basis for the interaction effect.

Figure 2: Ratings of drug problems by role and type of vignette



This effect (figure 2) appears to be similar in the case of drug problems; again, psychiatrists show a larger difference between their ratings than psychologists.

Figure 3: Ratings of **need for MHA assessment** by role and type of vignette



The effect is even more striking in the case of a proposed need for a MHA assessment (figure 3). However, in this case, although the magnitude of the difference between the ratings of psychiatrists is roughly the same as it is for the other significant interactions, the difference between the ratings of the psychologists is much smaller.

## **Chapter 4: Discussion**

## **Main findings**

- A range of psychological therapies is used with people with learning disabilities. Behaviour therapy was the most frequently used intervention, at least in terms of the amount of time spent applying it. Of the talking therapies, CBT appears to be the most used, and was rated as the most effective therapy with this client group. CBT was also rated as the talking therapy that psychologists felt most competent in administering.
- Perceived individual competence was consistently considered to be important in the amount of psychological therapy provided. Service resources and effectiveness emerged as important in the case of systemic therapy and psychodynamic therapy respectively, although only marginally so.
- 3. The level of the client's disability appeared to be an important factor. For example, both psychologists and psychiatrists rated psychological therapy as becoming significantly less effective and harder to do as the level of disability increased from mild to moderate and, similarly, from moderate to severe. In addition, they rated themselves as having had significantly less training in conducting psychological therapy with people with moderate and severe learning disabilities.
- 4. Diagnostic overshadowing appeared to be influencing the way in which clinicians appraised the symptoms of mental health problems in people with learning disabilities. Clinicians were less likely to consider diagnoses of schizophrenia and drug and alcohol related problems, and were less likely to consider psychiatric admission or the use of medication for people with learning disabilities. Psychiatrists appeared to be more likely to be affected by the diagnostic overshadowing bias than psychologists.

#### Case examples

In this chapter, a number of case-examples are employed (see methodology), and are intended to bring to life some the issues raised by the analyses. Each participant interviewed was asked to give their thoughts on three issues: the ways in which they developed their sense of competence as a clinician, the ways in which they assessed the effectiveness of their interventions and the role of psychological therapy for people with severe learning disabilities. These topics were chosen for elaboration because of their thematic importance throughout the analyses, indicating their salience to those working in learning disability services.

# The current status of psychological therapy for people with learning disabilities

When the idea for this research was first conceived, I wondered about the reality of Bender's (1993) assertion that clinical psychologists were depriving people with learning disabilities of the mental health services that were 'theirs by rights as citizens' (Bender 1993, p. 7). Seduced by Bender's controversial call to arms, and having worked in learning disability services both good and bad, I suspected that I would find a pattern of ambivalence and apathy toward psychological therapy with this client group. However, the findings from this large scale national survey of psychologists and psychiatrists working in learning disability services do not appear to support Bender's assertion that clinicians show 'therapeutic disdain' towards people with learning disabilities.

Clinical psychologists and psychiatrists working in learning disability services face the tremendous challenge of providing high quality treatment within a context of impoverished research, constantly evolving services and poor staffing. In spite of this, it appears that people with learning disabilities who have mental health problems have, by and large, access to a range of psychological therapies. Although it could be argued that the lack of research in this area is evidence in itself of 'disdain', perhaps the problem is no longer

primarily at the point of delivery, at least within learning disability services. This is likely to be the result of a large number of interacting factors. As well as examining some of the issues relating to the provision of different types of psychological therapy to people with learning disabilities, it is also important to consider the meaning and implications of the importance placed upon 'feeling competent' by clinicians, as well as the significance of service resources, the perceived effectiveness of psychological therapy with this client group, diagnostic overshadowing and the importance of the level of the client's disability.

# The use of different psychological therapies with people with learning disabilities

Research question 1 (p. 36) aimed to investigate the use of different psychological therapies currently undertaken with people with learning disabilities and the extent to which they were applied. The finding that clinicians rated CBT as the most effective psychological intervention with this client group (psychologists, for example, reported spending an average of nearly 4.5 hours a week providing CBT to their clients; see tables 3 and 5, pp. 47-9) supports evidence from other studies that have reported similar findings (e.g. Rush and Frances, 2001). Although many of the psychologists approached in this study indicated that they did indeed use behavioural techniques fairly widely (65% endorsed it as a method they use), more psychologists indicated that they used CBT (72%). Rush and Frances (2001) note from their study based in the USA that CBT was considered as an appropriate first line treatment for a number of psychological problems, including major depressive disorder, post traumatic stress disorder and obsessive compulsive disorder. In addition, CBT was rated as a second line option for bipolar disorder, schizophrenia, generalised anxiety disorder, conduct disorder, substance abuse and adjustment disorder.

The issue of the appropriateness of psychodynamic approaches with people with learning disabilities has been much discussed, and many of the major arguments

(for and against) have been covered in the introduction. A growing literature attests to the popularity of this approach with people with learning disabilities (e.g. Sinason, 1992; Strohmer and Thompson-Prout, 1994; Waitman and Conboy-Hill, 1992), although very few outcome studies exist (see Beail, 1995; Beail, 1998; Beail and Warden, 1996). The lack of outcome research in this field may play a part in its relative neglect as a therapeutic approach for people with learning disabilities, particularly in the current climate of evidence based practice. This pattern, however, is reflective of outcome research in this area in general, and is likely to exist for a wide variety of reasons (see introduction). In addition, however, there may be wider reasons why this approach is not seen as particularly appropriate for this client group. Firstly, the results from the regression analyses of the factors that are important in the provision of psychological therapy suggest that clinicians' sense of individual competence is more important than the perceived effectiveness of the therapy itself. This is further emphasised by the results of the multiple regression (table 8, p.54) of the factors important in the provision of psychodynamic therapy specifically, which showed that the clinician's sense of competence assumed particular important in the case of this style of working, accounting for 24% of the variance.

Achieving 'competence' in psychodynamic approaches is perhaps not as straight forward as achieving competence in approaches such as CBT. This has less to do with the difficulty of the technique and more to do with the opportunities for supervision, the availability of suitable clients and the service resources available to be able to commit to working intensively with a small number of individuals over a long period of time. Some of these issues are elaborated in case example 1 (below, table 12). Interestingly, 'J' (the psychologist portrayed in the case example) draws attention to the fact that, although psychodynamic approaches can be usefully applied with people with learning disabilities, it may be hard to address the types of problems that people with learning disabilities are often referred for. This may because someone else has referred them without them having necessarily been fully involved in the decision.

Table 12: Case example 1: working with people with learning disabilities using psychodynamic approaches

J is a clinical psychologist with several years experience working as a psychotherapist with people with learning disabilities. She works as the only psychotherapist on a multidisciplinary team.

- '...Effectiveness for me is in the process, not the outcome. I think that I can work with people with more severe learning disabilities, but I get the impression that, although I can help them within the session, they find it hard to use the ideas outside of the session. I guess you could say that, in some sense, it is effective, but in other ways it isn't...'.
- '...Sometimes I find that, although a client can work in a psychodynamic way, it's hard for them to address the reason for referral in this way. So it's not like they can't make use of it, it's just that they can sometimes only make use of it in a limited way...'.
- "...Some clients that I see are there because they are the ones who either have someone reliable who can bring them to the session or can manage themselves..."

That clinical psychologists working with people with learning disabilities should consider systemic approaches useful is perhaps no surprise. Many people with learning disabilities live in family or group settings for much of their lives, and it is therefore no surprise that the system they live in needs consideration when devising a treatment plan. As Berger and Foster (1986) note, the birth of a child with a disability or a later diagnosis of a handicapping condition into a family creates unusual demands on the system. Consequently, an understanding of the family system is crucial for effective intervention; to focus solely on the individual with the so-called 'problem' is seen as inappropriate. In the same way that families can experience difficulties in coping with a member who has a learning disability, group residences can suffer from problems at a systemic

level. The characteristics of the relationships amongst the individuals running them, the quality of the care, the quality of the environment and the opportunities for living a 'normal' life can all impinge upon the mental health of residents. In addition, people with learning disabilities often come into contact with a large number of overlapping social systems as a result of the different levels of care that society provides (Vetere, 1993), and the potential for any one of these to have a dysfunctional impact upon the individual is considerable.

The obvious need for systemic approaches to the treatment of mental health problems in people with learning disabilities is reflected in a number of articles that have appeared in professional journals such as Clinical Psychology (previously Clinical Psychology Forum), setting out the benefits of working in this way and appealing for a concerted effort at consciousness raising (e.g. Chowdhury, 1992; Donati, Glynn, Lyngaard and Pearce, 2000; Evans and Midence, 1999). However, this has not been matched by a similar interest in treatment evaluation, and outcome studies of the effectiveness of systemic therapy in people with learning disabilities are, to date, largely absent. Unlike psychodynamic approaches with this client group, there is also a general lack of literature on the subject. This is problematic for a number of reasons. For example, given the demonstrated importance of clinicians feeling that the therapy they are using is clinically effective, information regarding effectiveness is essential. Achieving competency in an environment lacking even basic discursive literature is also likely to be difficult.

Rush and Frances' (2001) survey of nearly 100 'experts' on mental health in people with learning disabilities in the USA suggests that, overall, the three types of intervention that were most highly recommended were applied behavioural analysis, managing the environment and client and family education. This was the case for clients of all levels of disability and with both mild and more severe psychological problems. Of the talking therapies that were applied with people with learning disabilities, Rush and Frances (2001) found that CBT was the most readily utilised. Their data reveal that CBT was considered as an appropriate first line treatment for a number of psychological problems, including major depressive disorder, post traumatic stress disorder

and obsessive-compulsive disorder. In addition, CBT was rated as a second line option for bipolar disorder, schizophrenia, generalised anxiety disorder, conduct disorder, substance abuse and adjustment disorder. Psychodynamic psychotherapy was not considered as a suitable first or second-line treatment for any of the disorders listed on axis 1 of DSM-IV, and systemic approaches were ignored completely. This appears to suggest that, as far as the USA is concerned, although talking therapies are certainly considered, they are seen as far less useful than other, non-interactive strategies.

# Competence, effectiveness and service resources

Research question 2 aimed to assess the contribution of competence, effectiveness and service resources to the provision of psychological therapy with people with learning disabilities. The importance of each of these variables is discussed below.

### Perceived individual competence

Of the components that were hypothesised to affect the provision of psychological therapy to this client group, individual perceived competence appeared to provide the most consistent contribution. It was a significant predictor of the provision of psychological therapy in all cases where the overall regression was significant, accounting for between 2-24% of the variance in the dependent variable (depending on what type of therapy was under consideration). The development of individual competencies in providing psychological therapy initially takes place during training, both for psychologists and psychiatrists (Day, 1999; Roth and Fonagy, 1996). Students are required to demonstrate clinical competence in a range of therapeutic approaches, particularly in those that have developed an empirical evidence base (Roth and Fonagy, 1996). However, training in providing psychological therapy to people with learning disabilities is very limited when compared to training received in providing psychological therapy to adults from the general

population. The paucity of training available in psychological therapy for this client group raises clear questions regarding the level of expertise that clinicians have in this area. However, although early studies tended to suggest a clear relationship between therapeutic outcome and expertise, later studies have been more equivocal. Nonetheless, on the basis of a careful meta-analysis of 36 studies, Stein and Lambert (1995) report moderate effect sizes for the relationship between expertise and outcome. Similar findings are reported when professional training specifically is considered (as distinct from experience per se). For example, Burns and Nolen-Hoeksema (1992) examined the differences in therapeutic outcome between those classed as 'novices' in CBT and those who had received more than 4 years of training, finding that the patients of novice therapists improved significantly less than the patients of those with more experience.

Given that the findings of the present study suggest that perceived levels of competence accounted for nearly 10% of the variance in the number of hours of (generic) psychological therapy provided to this client group (5% when psychologists were considered separately), and given that other research has shown therapeutic competence to be important in terms of clinical outcome, it is also important to consider some of the psychological components that are subsumed under 'feeling competent'. This will, in turn, allow a deeper understanding of the different ways in which competence affects the provision of psychological therapy.

Connell and Wellbourn (1990) have proposed a needs theory of individual competence (see introduction). This theory appears to provide some important insights into why perceived competence might be so important when trying to identify some of the factors important in the provision of psychological therapy to this client group. For example, the way in which it highlights the role that competence plays in the process of engagement and disaffection with a task demonstrates how important it is likely to be in influencing whether or not clinicians are able to continue providing therapy when the gains they are making may not be immediately obvious. Although the behaviours and emotions associated with engagement are likely to encourage a clinician to continue

providing psychological therapy, those associated with disaffection are almost certainly likely to reduce its provision. We might hypothesise, then, that the low levels of service provision available to people with learning disabilities who have mental health problems (see introduction) has in fact been affected by the generally held belief that few clinicians are able (i.e. competent) to help people with learning disabilities using psychological therapy.

Many authors have also attempted to provide a more detailed account of how self-efficacy affects decision-making and performance by considering its relationship with other variables. For example, Wood and Bandura (1989) have considered self efficacy in relation to past performance on a task, the individual's personal goals and the analytic strategies that they. The model suggests that, as people begin to form a self-schema concerning their efficacy (competence) through further experience, their perceived self efficacy influences performance both directly and through its strong links on personal goal setting and proficient analytic thinking (Wood and Bandura's term 'analytic thinking' can be thought of as analogous to problem solving ability). Personal goals, in turn, enhance performance through their influence on analytic strategies.

Thus, as well as perceived competence having an effect on the manner in which a clinician might undertake a task (i.e. in an engaged or a disaffected way; see Connell and Wellbourn, 1990), it also influences the goals that clinicians are likely to set themselves. In a therapeutic situation, this might translate into clinicians with more experience feeling more competent, and therefore setting themselves more appropriate treatment goals than a clinician with less experience and, in turn, less self efficacy (competence). Some of these points are emphasised by the case example presented in table 13 (p. 76), which summarises some of the day-to-day difficulties that clinicians face in terms of developing their sense of competence. Importantly, the clinician interviewed highlights the lack of specific training resources in the area of mental health and learning disability.

# Perceived effectiveness of psychological therapy

Overall, the extent to which clinicians rated psychological therapy as effective or not with people with learning disabilities appeared to contribute little to their decision whether or not to use it. There were, however, a number of exceptions to this. One exception appeared to be in the case of psychodynamic therapy, although the statistical significance of the effectiveness variable in this case belied a very small contribution to the actual variance in the dependent variable (2%). In addition, there was some evidence that psychiatrists placed more emphasis on the notion of effectiveness than psychologists, finding it to be fairly important in the cases of both group therapy and systemic therapy.

The importance of perceived effectiveness in the provision of psychodynamic therapy overall, and group therapy and systemic therapy in the case of psychiatrists is interesting, as this ignores the one area (CBT) where a literature relating to effectiveness with this client group is beginning to develop. This raises the question as to whether clinicians find other methods of deciding whether or not psychological therapy is effective with this client group. For example, decisions about effectiveness may rely on their own assessments of whether or not clients are being helped by their interventions, either on the basis of pre and post measures of symptom severity and functioning, on the basis of direct feedback from their clients or feedback from other staff and carers (see also case example 2, below). However, it is also possible that personal impressions of effectiveness are also formed in a less systematic way. For example, we might expect a clinician who has a particular passion for a specific therapeutic approach to apply that approach fairly indiscriminately. Similarly, it may be the case that clinicians have had success with a certain therapeutic approach with a different client group, and are inclined to use it with people with learning disabilities in the belief that it will be helpful.

It may also be the case that the focus in the literature on *process* as opposed to *outcome* with this client group has had a significant effect on what clinicians regard as important when considering whether or not to provide a certain type of psychological therapy. Much of the literature pertaining to CBT, systemic therapy and psychodynamic therapy focuses on the different skills that clinicians

are likely to need (e.g. Stenfert-Kroese, Dagnan and Loumidis, 1997; Sinason, 1992; Strohmer and Thompson-Prout, 1994; Waitman and Conboy-Hill, 1992). This may have the paradoxical effect of orienting clinicians to skills-based clinical decision making to the exclusion of other forms of decision-making. Similarly, a likely reason for the lack of overall importance placed on effectiveness by clinicians might be that the amount of research literature relating to the effectiveness of psychological therapy for people with learning disabilities is relatively limited, presumably making judgements relating to clinical effectiveness more difficult to make (e.g. Nezu and Nezu, 1994).

The overall reluctance of clinicians to consider notions of effectiveness, coupled with the finding that, where it is considered, this is unlikely to reflect the research evidence for its clinical efficacy, raises questions regarding the status of evidence based practice within this field. The lack of importance placed on research need not, however, be seen as entirely negative. Salkovskis (2002) notes that, although the current emphasis on evidence-based practice has led to a welcome bid to improve the empirical foundations of many psychological therapies, it also has the potential to distort and undermine new and innovative approaches to treatment. In relation to the continuing development of CBT, Salkovskis (2002) suggests that, because psychological treatments require validated theoretical frameworks around them, an approach to effectiveness that focuses solely on narrow conceptions of outcome, such as randomised controlled trials, is likely to be misleading.

This has several implications. Firstly, we might hypothesise that if traditional notions of clinical effectiveness are too simplistic for those from the normal range of intelligence, they are equally likely to be too simplistic for people with learning disabilities. In many ways, the development of psychological therapy for this client group is still at the stage of what Salkovskis (2002) refers to as 'experimental studies and related research'. Clinicians working in learning disability services are faced with pressure to focus on outcome studies as an indication of clinical effectiveness, when in reality they require a broader basis for demonstrating effectiveness. Secondly, the model has implications for continuing professional development (CPD). For example, the current emphasis

as far as clinical effectiveness is concerned is on the dissemination of high-quality outcome studies (Chambless and Ollendick, 2001; Sackett, Rosenberg and Grey, 1997). Given that the development of psychological therapies for people with learning disabilities is still, relatively speaking, in its infancy, this type of narrow focus 'leapfrogs' (Salkovskis, 2002) the developmental stages that research needs to go through. Perhaps what clinicians require is a broad range of information relating to current theoretical, experimental and service developments, as well as information from randomised controlled trials and meta-analyses (if and when such information becomes available). In this way, they might be more encouraged to use the notion of effectiveness in their decision making process when considering the role that different psychological therapies have to play in helping their clients. Again, some of these points are elaborated in the case description given in table 13.

Table 13: Case example 2: the role of perceived competence and effectiveness

'A' is a consultant psychologist working in a service for people with learning disabilities and challenging behaviour. She qualified 20 years ago, and has worked in LD services for the majority of her career. She has worked in her current service for several years.

'...conferences can help, but often it's a case of going to conferences that are related to what you want but are not specifically about what you want because they're not really aimed at people with learning disabilities – they're aimed at people with normal intelligence. In the end, this can sometimes make you end up feeling less competent, because you're still having to adapt what you do using your own skills and imagination...'

"...having worked in a non-learning disability setting helps, because it shows me psychological interventions working in a more profound way. At least then you know what you're trying to do with these people does work..."

'...people with learning disabilities have the same problems as other people, so there's no reason why the same approaches can't be used. But you have to modify both the process you use and your goals. So in the end, it's harder to do and the outcome is more modest...'

"...research studies do help, but to be honest I pay just as much attention to feedback from the clients themselves and from their other carers. I do my own outcome measures as well, though, so I can use those to help me make judgements...".

### Service Resources

Although resources for people with learning disabilities and mental health problems are known to be inadequate (Day, 1999; Emerson, 2001; Rose, 2001), the data collected in this study did not support the hypothesis that this would in turn affect service provision. This is surprising, given that one might reasonably expect service resources, particularly staff numbers, to strongly influence whether or not people with learning disabilities are offered direct psychological therapies (which tend to be relatively staff-intensive).

There are a number of possible reasons for this finding. Firstly, it is possible that the way in which service resources were measured (essentially, a calculation of available clinicians) does not reflect the true nature of the aspects of a service that make it 'well resourced'. For example, it may be that access to libraries with current journals relevant to treating mental health problems in people with learning disabilities is an important factor, as may be links with local clinical psychology training courses and other professionals working in the field. In addition, there may also be important aspects of the structure as opposed to the size of services that render them more or less able to provide psychological therapy. For example, there may be strict boundaries concerning who provides therapy in the service. Whereas some services may take the approach that, with appropriate supervision, assistant psychologists, psychiatrists, occupational therapists, educational staff and other MDT members can provide certain types of psychological intervention, others may take the approach that psychological therapy is only appropriately carried out by clinical psychologists.

As well as structure playing an important part in the allocation of resources, service *ethos* may also play an important role. The apparent lack of staff resources as a key factor in deciding whether people with learning disabilities are offered direct psychological therapies suggests that there may be a far less straightforward relationship between resources and provision of a range and choice of services for people with learning disabilities. Services for people with learning disabilities are known to vary widely across the UK (e.g. Bouras,

Brooks and Drummond, 1994; Department of Health 'Valuing People', 2001; Mason, 1998), and Bouras, Brooks and Drummond (1994) note that staff characteristics and organisational practices are two of the most important factors in determining the manner in which a service is structured. It is conceivable, therefore, that some services, due to staff and management considerations, structure their services in such a way as to affect the provision of psychological therapy, perhaps by influencing who carries out different therapeutic activities and in what setting (e.g. in clients' homes or workplaces, as opposed to a more traditional therapy model where clients are seen in dedicated service settings). Finally, services that are poorly staffed and under considerable waiting-list pressure are unlikely to be able to provide as much resource-intensive direct therapy as well resourced services. Therefore, it should also be considered that this finding might reflect the fact that the current study measured attitudes and self-reported behaviour as opposed to a more objective measure of actual behaviour and services offered. Put differently, many clinicians may be well aware that it is now increasingly recognised that people with learning disabilities can indeed benefit from psychological therapy, and may be keen not to show any signs of what Bender (1993) termed 'therapeutic disdain'. However, in reality waiting lists and other resource pressures may mean clinicians are less able to offer the amount and range of psychological therapies they would like to.

# The role of level of disability

Research question 3 (p. 36) aimed to investigate the importance of a level of client's disability in determining their appropriateness for psychological therapy. Table 9 (p. 56) tells an interesting story; it shows that psychological therapy is considered to be less effective and more difficult to deliver as the level of disability increases, but that this is not offset by an increase in the reported likelihood of recommending the use of medication. Although psychiatrists were slightly more likely to turn to medication as a treatment for mental health problems in people with severe learning disabilities, their mean rating for this was only around 2 (out of 5), indicating a general sense of reluctance. It may of course be the case that, just because psychologists say that psychological

therapy is far less effective for this client group, they still provide it anyway, as it may equally be the case that psychiatrists recommend medication as a first line treatment, despite feeling that it is unlikely to be very effective. Certainly, the prescribing of medication for behavioural and psychological problems in this client group has received a great deal of interest recently. Both psychologists and psychiatrists have warned against the over prescribing of psychotropic medication in this client group (e.g. Clarke, 1997; Clarke, 1999; Stenfert-Kroese, Dewhurst and Holmes, 2001), highlighting the lack of an evidence base for much of the prescribing that undoubtedly goes on and questioning the validity of psychiatric diagnoses in those with more severe disabilities.

Commonly, people with more severe disabilities who require intervention due to a mental health problem are worked with indirectly (Caine and Hatton, 1998; Rush and Frances, 2001). The vast majority of respondents in this study (97% of psychologists and 98% of psychiatrists) indicated that they did indeed work in this way with clients, although it was not possible to conclude from these data whether or not this applied more in the case of people with severe learning disabilities or not. Evidence suggests, however, that this is likely to be the case. Participants in this study indicated that, as well as considering effectiveness to be an important part in whether or not a client received a specific kind of therapy, psychological therapy was less effective with people with more severe disabilities. Thus, it is reasonable to assume that people with more severe learning disabilities were far less likely to receive it, and consequently more likely to be worked with indirectly (c.f. Rush and Frances, 2001).

Some useful reflections on working with people with severe learning disabilities are provided in the following case example (table 14).

Table 14: case example 3: Psychological therapy with people with severe learning disabilities

W is a consultant clinical psychologist with nearly 20 years experience. She works as one of 2 psychologists on a MDT in a community-based service, providing a wide range of health services to clients with learning disabilities.

- "...the process of working with this client group (people with severe disabilities) is basically boring, although that is not to say thinking about what the problem is or what is going on in the mind of someone with a severe or profound disability is boring...".
- '...Psychological therapy is possible with this group, I suppose, but I'd prefer someone else to do it. I know the work can have tremendous results, but it doesn't really feel what I'm trained to do...'
- "...There is a very clear need for psychological therapy with this client group, perhaps even more so than other clients. They suffer multiple indignities and abuse in so many different ways..."

Case example 3 (table 14) provides some interesting reflections on psychological therapy with people with severe learning disabilities, highlighting some of the issues relating to competence and effectiveness but also highlighting the issues of motivation to work with this client group. As well as sometimes presenting with extremely challenging behaviour, the 'attractiveness' of working with this client group is perhaps diminished by the effort psychologists feel they have to put in to obtain even modest results. Whether this amounts to what authors such as Bender (1993) have termed 'therapeutic disdain' is debatable. As Bender (1993) notes, psychological therapy involves intensely relating to another person over quite a long period of time. This becomes more difficult, aversive and energy consuming when the person is seen as 'unattractive'.

Bender goes on to argue that it is internalised feelings of prejudice, stereotyping and hostility, as opposed to issues such as how competent clinicians may feel in helping this client group, which lead professionals to deny that that there is an obligation to provide psychological therapy to people with severe learning disabilities.

What seems clear from this research, however, is that clinical psychologists working with people with severe learning disabilities are likely to take issues such as how competent they feel seriously. In addition, clinicians indicated that they found working with people with more severe disabilities more challenging and that they felt they had less training in this aspect of their work (see table 8, p.53), both of which are factors that are likely to affect a clinician's perceived level of competence. Although some of Bender's 'therapeutic disdain' may be partly responsible for clinicians not undertaking more training, or may even play a role in clinicians finding working with this client group 'hard' (i.e. for prejudicial reasons, as opposed to its relationship with their feelings of competence), it also seems that they have genuine concerns regarding their personal competence in delivering services to people with severe learning disabilities. These concerns are likely to be rooted (at least partially) in the lack of clinical literature addressing psychological therapy with this client group and the lack of easily accessible resources that clinicians can use to develop their skills.

# Can psychological therapy help people with severe and profound disabilities?

Although it is undoubtedly important that some of the data from this research establish the diminishing likelihood of people with moderate and severe learning disabilities receiving psychological therapy, it is also important to consider whether this client group can in fact make use of psychological therapy in the first place. It is only relatively recently that attempts have been made to use psychological therapy with this client group, and it remains a contentious issue (Sinason, 1992). Popular texts on the treatment of behavioural and mental

health problems in people with learning disabilities commonly only refer to behavioural and environmental management strategies (e.g. LaVigna and Donellan, 1986; Remington, 1991), and although texts certainly exist describing the psychological treatment of people with learning disabilities (e.g. Stenfert-Kroese, Dagnan and Loumidis, 1997; Sinason, 1992; Strohmer and Thompson-Prout, 1994; Waitman and Conboy-Hill, 1992), the behavioural mentality pervades (Rush and Frances, 2001).

One of the most likely reasons for the reluctance of clinicians to consider the use of psychological therapies with this client group is their heavy reliance on language (they are, after all, often referred to as 'talking therapies'). As Clements (1997) points out, CBT is heavily reliant on the verbal representation of information, a criticism that can be fairly levelled at the majority of psychological therapies. However, this need not be the case. Clements notes that information enters the processing system through a number of channels—auditory, tactile, visual, olfactory and kinaesthetic. We may then process this information on any number of levels, which may or may not include language-based representations of knowledge. Clements (1997) gives the example of a piece of music, which can be processed emotionally, intellectually (perhaps in relation to structure), by comparison to other pieces etc. The key to the development of psychological therapies for people with learning disabilities who are less able to use language may be to develop other ways of representing, processing and communicating knowledge.

An additional explanation for the reluctance to consider alternatives to behavioural and environmental solutions to mental health problems in this client group is that much of the existing literature is process rather than outcome focussed. One of the few psychological interventions to be empirically validated with people with severe learning disabilities is relaxation training. For example, Lindsay, Fee, Michie and Heap (1994) describe a successful attempt to teach relaxation skills to participants with IQs below 40 using cue words linked to a behavioural relaxation-training programme. Results showed reductions in self-reported and key informant reported anxiety and improvements in levels of concentration. Similarly, Hegarty and Last (1997) used physiological and

postural indicators of anxiety to demonstrate that behavioural relaxation training can be used to provide lasting improvements in the levels of anxiety in people with severe and profound learning disabilities.

Although outcome evidence of psychodynamic approaches with people with learning disabilities is generally lacking (though see Beail 1995, 1998 for notable exceptions), indirect evidence exists to suppose that the process of understanding and validating the communications of individuals with severe learning disabilities leads to improvements in their behaviour and mental health. As Porter and Ouvry (2001) note, people with severe and profound disabilities have limited ability to use language in any form (e.g. speech, signing or use of symbols), and are more likely to be communicating at an early level, involving signals such as reflex responses, actions, sounds and facial expression. The responsibility for interpreting these signals in accordance with the feelings or meaning of the person is very great, and it can be difficult to verify whether or not one has made the correct interpretation because the person concerned is more likely to acquiesce than contradict (Sigelman et al., 1981). researchers (e.g. McConkey, Morris and Purcell, 1999; Stillman, Williams and Linam, 1997) have provided evidence that staff working in services for people with severe and profound learning disabilities often overestimate learners' understanding of verbal cues and have difficulty adjusting their communication to the person's level. This, in turn, is associated with higher levels of behavioural distress in residents.

Given the benefits that providing reflective understanding may convey to people with severe and profound disabilities, it is possible to begin to understand some of the important psychological mechanisms involved in helping this client group. Although their ability to take part in prototypical psychological therapy is almost certainly limited, that is not to say that helping them psychologically is not possible, and in fact is likely to be both possible and beneficial.

As well as considering behavioural and psychodynamic approaches, it is also important to consider systemic approaches with people with severe and profound disabilities. The combination of individual and system-wide work inherent in systemic and family approaches is likely to make it particularly

appropriate with this client group, as it enables the clinician to intervene at a number of levels (Vetere, 1993). Many researchers (e.g. Evans and Midence, 1999; Goldberg et al., 1995) have commented on the negative impact that certain systems can have on people with learning disabilities, and it seems probable that this effect is likely to be even greater for people with severe and profound disabilities. For example, because of their support needs, they are often more reliant on family, day services and nursing care than people with milder disabilities, yet sometimes these systems can operate in such a way as to have a negative impact on their lives. Where this is the case, it is important to consider both the individual's response to the system (often conveyed in terms of 'symptoms' or challenging behaviour) and the system itself (Evans and Midence, 1999) in order to bring about successful and lasting change. However, although the theoretical basis of systemic interventions with this client group seems strong, there is little outcome evidence to confirm its validity.

# The significance of the diagnostic overshadowing bias

Research question 4 (p. 36) aimed to assess the contribution of the diagnostic overshadowing bias to the provision of psychological therapy to this client group. The data analyses suggested that some degree of diagnostic overshadowing was taking place. Clinicians were less likely to consider diagnoses of schizophrenia and drug and alcohol related problems, and were less likely to consider psychiatric admission or the use of medication for people with learning disabilities. In addition, psychiatrists appeared (at least in some instances) to be more likely to be affected by the diagnostic overshadowing bias than psychologists.

However, although the diagnostic overshadowing bias was demonstrated statistically, it is not clear that it would have any appreciable clinical implications. This reflects one of the more common criticisms of the diagnostic overshadowing methodology, which argues that overshadowing has yet to be demonstrated outside of the particular analogue methodological approach common in this type of research. In a recent review article, Jopp and Keys

(2001) note that, of the 12 studies they cite, 10 used some variation of the classic methodology employed in the first series of diagnostic overshadowing studies (Levitan and Reiss, 1983; Reiss Levitan and Szyszko, 1983; Reiss and Szyszko, 1983), which was also employed in this study (see methodology). As Jopp and Keys (2001) note, given that diagnostic overshadowing has not been established outside of one particular methodology, it could be argued that it is an inconsequential finding (i.e. clinically insignificant) or even a methodological artefact.

Jopp and Keys (2001) argue that, despite the shortcomings of diagnostic overshadowing research noted above, several indications suggest not only that diagnostic overshadowing directly affects some types of clinical judgement but may also influence the overall level of treatment of people with learning disabilities and mental health problems. They go on to argue that until direct evidence is presented that overshadowing is not occurring in actual clinical settings, it remains reasonable to hypothesise that, on the basis of the analogue findings, diagnostic overshadowing is indeed occurring. They conclude that it is more plausible to argue that the lack of findings regarding the clinical significance of the diagnostic overshadowing bias is due to the limited research done to date, rather than being a commentary on the robustness and relevance of the overshadowing phenomenon.

However, the interpretation of this finding is complicated by the existence in the present study of a significant interaction effect between the type of vignette presented (i.e. learning disability or normal range) and the role of the respondents (i.e. psychiatrist or psychologist), the direction of which implies that psychiatrists are more affected by the bias than psychologists. Specifically, psychiatrists were more likely to diagnose schizophrenia and drug problems in those from the normal range of intelligence than those with learning disabilities, this effect being greater than that observed for psychologists. In addition, psychiatrists were more likely to recommend a Mental Health Act assessment for those from the normal range of intelligence, and again this effect was significantly more pronounced than observed in psychologists (see figures 1-3).

Thus, two forms of bias are implied by these results – the classical diagnostic overshadowing bias, demonstrated by the fact that clinicians (psychologists and psychiatrists together) were less likely to diagnose mental health problems in people with learning disabilities, and a role bias, such that psychiatrists were more likely than psychologists to diagnose mental health problems in 'patients' from the normal range than 'patients' with learning disabilities. This role bias is likely to have contributed to the finding that psychiatrists appeared to be more susceptible to the bias than psychologists.

What remains, then, is to consider whether the findings reported herein are sufficient evidence that the diagnostic overshadowing bias is a methodological artefact as opposed to a clinical reality. Certainly a great deal of evidence exists to suppose that a number of judgement biases do indeed have a basis in clinical reality. Extensive reviews of studies using clinically-based methodologies such as case-note reviews and clinical audits (e.g. Garb, 1998; Lopez, 1999) note both diagnostic and treatment biases relating to race, gender, age, social class, geographical location, HIV status, weight, religion and political viewpoint. That diagnostic and treatment biases seem so widespread is perhaps good evidence to suppose that the diagnostic overshadowing bias in clinicians working with people with learning disabilities should also have a basis in clinical reality.

# Limitations of this study

There are a number of important weaknesses to this piece of research. Firstly, although the response rate is comparable with similar studies (e.g. Nagel and Leiper, 1999), it still only represents a response rate of around one in three. It was not possible to assess whether there were any differences between those who did and those who did not respond, and it is possible that those who declined to participate did so because they did not provide much in the way of psychological therapy to their clients. In addition to the response rate, the sampling was also affected by the fact that there is no centralised register of clinical psychologists in the UK. Thus, although great effort was made to track down as many psychologists as possible working in learning disability services,

it is inevitable that some were missed. However, a number of factors make it likely that the sample described in this study was reasonably representative of clinical psychologists and psychiatrists working in the UK. The participants who responded represented the majority of regions throughout England, Scotland, Wales and Northern Ireland, and covered a range of ages and levels of experience as well as a variety of settings.

Secondly, the trade-off required in questionnaire-based research between detail and brevity probably leads to a number of complications. For example, brief definitions of the different styles of psychological therapy would have added little to the length of the questionnaire but may have improved its validity. Psychologists and psychiatrists doubtless have their own understanding of the difference, for example, between behaviour therapy and indirect work, but perhaps use them interchangeably or in different ways. Similar problems, where the forced choices imposed by questionnaire methods threaten the validity of the measure, may have arisen in those questions where the effect of the level of the client's disability on their ability to use psychological therapy was explored. For example, clinicians may have held differing conceptions of the extent and range of difficulties that represent the different levels of disability (mild, moderate and severe). Although the types of difficulty that such individuals are likely to experience are covered in diagnostic manuals such as DSM-IV, there is no single accepted definition of the precise differences between the levels of disability. This may, in turn, have lead to some differences in the way in which these concepts were interpreted by clinicians, and thus have affected the validity of the findings.

Thirdly, and in part due to the problems outlined above in relation to the brevity of the questionnaire, it is possible that the way in which some of the variables were operationalised was problematic. For example, in the case of the notion of service resources, this was little more than a calculation of the number of clinicians available. As noted earlier, it is likely that service resources in their entirety are far more complicated than this, incorporating the cultural ideas held within the service regarding the appropriateness of therapy and the people most appropriate to deliver it, the resources of the services with which it is linked and

the wider context of the service setting (e.g. whether it is in an inner city area or an affluent suburban area). In addition, although respondents were asked to indicate the number of clinical psychology trainees that they had in their service, they were not asked about the number of SHOs (their medical counterparts). This was essentially an oversight on the part of the author, probably borne from his own status as a trainee clinical psychologist. Although they were omitted from the sample for the same reason that trainee clinical psychologists were (i.e. they are not considered to be fully qualified in their field, and are often only on short-term placements in the service), they could usefully have been included in the list of potential service resources.

Different, but none-the-less important issues, are associated with the way in which the notions of competence and effectiveness were operationalised. Firstly, it has hopefully been shown that the concepts of competence and effectiveness are likely to be somewhat complex. In the case of competence, for example, as well as being closely associated with a number of other factors (such as previous experiences), it is likely to be comprised of different components itself (e.g. emotional and behavioural facets). This raises the obvious question as to how accurately simply asking a clinician how competent they feel in delivering a certain type of therapy is in gauging their level of true competence. It is perhaps the case that a more multifaceted approach to the measurement of these two concepts was required, encompassing elements of emotional competence (e.g. different affective states associated with selfefficacy) and behavioural competence (e.g. clinical efficacy) as well as overall attitude. It is entirely likely that the over-simplification of what are almost certainly quite complex psychological concepts was also responsible for the moderate reliability coefficients associated with both the competence and the effectiveness variables.

A further consideration related to the way in which various components of the questionnaire were measured was the decision not to employ a central anchoring point on any of the scales. This decision was made principally to avoid the tendency of a 'don't know' response set and to encourage clinicians to form some kind of opinion in relation to the questions being asked. On reflection, a

more valid and sophisticated approach might have been to provide a mid-scale anchor point that corresponded to something other than a 'don't know' answer but nonetheless provided the respondent with some additional guidance as to the meaning of the middle of the scale.

As with other research studies that have attempted to assess the importance of the diagnostic overshadowing bias, conclusions relating to its validity remain The methodology used in this study sticks closely to the hard to draw. traditional methodology employed in studies that seek to answer questions regarding diagnostic overshadowing, but it seems likely that a new methodology is required, if only because we are still unable to say whether or not such a bias is actually likely to affect the behaviour and real-life decision making of clinicians. In other words, it is hard to conclude from the 'vignette approach' to the assessment of diagnostic overshadowing whether or not this is how clinicians will actually behave. The relationship between attitudes and behaviour is known to be extremely complex, and even when considered at the most basic level, the importance of the notion of 'intention' is central (e.g. Wood and Bandura, 1989). Although the vignette methodology employed in this study can be seen as an attempt to get closer to what a clinician may actually intend to do in a clinical situation, it is also likely to be a vast oversimplification of the types of factors that become important in a clinical situation. For example, the ability of the client to communicate their distress, the presence of corroborating evidence from friends or family members and the experience of the clinician in relation to the assessment and formulation of psychological problems in people with learning disabilities might be just some of the important factors not assessed using this type of methodology.

An alternative to the traditional methodology of comparing the responses of clinicians on two different kinds of vignette might be to use videotaped interviews with 'patients', the logic being that clinicians would be making decisions about the diagnosis of people on the basis of more realistic information. A different method again might involve having clinicians read a brief referral letter similar to the vignettes used in traditional diagnostic overshadowing research and then interview a 'patient' who corresponds to the

information they receive. Asking them to provide a diagnosis on this basis might again represent a more clinically life-like situation.

Lastly, it is useful to consider the validity of measuring the extent to which clinicians provide psychological therapy using a questionnaire measure, as there are likely to be a number of problems. For example, there is no way of checking if the respondents do actually do what they indicate they do on the questionnaire. Ordinarily, we might suppose that there is no reason to think that they would not; however, in relation to the provision of psychological therapy to people with learning disabilities, there may have been a considerable element of social desirability (or 'faking good') affecting their responses. Further, the internal consistency of the questionnaire used was only moderate, leading to the possibility that improvements within its structure would have lead to subsequent improvements in its usefulness as a measurement tool. In addition, questionnaires can be inherently frustrating for people, with respondents feeling that the boxes and scales do not reflect their experiences. Unfortunately, the kinds of quantitative questions asked in this study require a large sample of easily categorised responses, making alternative methodologies impractical.

The validity of using a questionnaire to assess what clinicians actually do may also be affected by a certain amount of 'hypothesis guessing' on the part of the respondents (e.g. Barker, Pistrang and Elliot, 1994). In such cases, the respondent attempts to guess the underlying aim of the research, and in so doing may provide answers that they suppose are suited (or, presumably, particularly unsuited!) to the research question. This may particularly be the case when using clinical vignettes, as the questions associated with them provide the respondent with an additional opportunity to guess the underlying issues that the researcher is attempting to address.

Many of the criticisms that can be levelled against this piece of research are a function of attempting to gain information from a large sample of very busy people. Considering the legitimacy of many of these criticisms, perhaps one of the overall conclusions that can be drawn relates to overall methodology rather than its individual components. Most of the questions asked in this piece of research could also be asked of a far smaller population in a much more detailed

way. This would allow consideration of many more of the complexities of issues such as competence and self-efficacy, and perhaps also allow a more novel approach to the issue of diagnostic overshadowing.

# **Clinical implications**

It is hard to escape the fact that psychological therapy for people with learning disabilities is very much in its infancy. Clinicians working in this field have to make use of limited resources, often adapting what is available from work undertaken with those with normal intelligence to the needs of their own clients. The aim of this section is to suggest, based on the findings of this research, some of the ways that services may readily improve the access of people with learning disabilities to high quality psychological therapy.

# Continuing professional development (CPD)

The development of a CPD programme that focuses on *clinical effectiveness* in as broad a way as possible, using resources that go beyond the simple dissemination of outcome studies would enable clinicians to develop a wider understanding of the ways in which they might treat mental health problems in this client group. It might include information on relevant theoretical developments, as well as information from other services on what they find effective. It might also include the development of their own audit and research strategy, which would enable them to evaluate their own routine clinical work and begin to build up an evidence base for psychological therapy with this client group.

It is also important to develop CPD programmes that address the importance of perceived individual competence in a very specific way. The research described herein suggests that the notion of competence is extremely important to clinicians, but that it is hard to develop. This is because of the lack of specialised resources for people with learning disabilities who have mental

health problems, but also limited opportunities for advanced training in different therapeutic approaches targeted at this client group.

Lastly, CPD is likely to assume greater importance as the role of clinical psychologists and psychiatrists working in learning disability services changes in response to the recent developments in health policy (Department of Heath, 2001). Baum and Webb (2002) conclude that the policy is likely to have a substantial impact on the way in which clinical psychologists work, requiring the increasing use and development of mainstream psychological models for this client group, applied in generic healthcare settings. This, in turn, is likely to require the development of a wide range of new skills, presumably supported within a CPD framework.

## Strategic planning for people with severe disabilities

Perhaps one of the greatest concerns raised from this study is that clinicians appear to feel they have little access to effective psychological treatments for people with severe learning disabilities. It is important to develop a set of coherent service strategies for assessing, diagnosing and treating mental health problems in people with severe learning disabilities. For example, clinical audit procedures may be used to assess the types of service offered to this client group (e.g. Parry, 1992). This would allow the relationship between people with severe learning disabilities and the type of treatment they receive (e.g. medication, psychological therapy) to be monitored, ensuring that they do not 'slip through the net'. Maxwell (1984) usefully suggests 6 criteria by which a service can be judged successful, noting that it should be relevant, equitable, accessible, acceptable, effective and efficient. Applied to people with severe learning disabilities, this would translate into ensuring that they are not overmedicated, they are not ignored because they are viewed as 'difficult to treat', that the service provides something which people with severe learning disabilities see as meaningful and finally that the service makes best possible use of its limited resources.

## Reducing clinical bias

Although the status of the diagnostic overshadowing bias remains unclear, Garb (1998) gives some useful advise for avoiding clinician bias, including making more use of standardised assessment tools, being wary of making judgements based on little information and attempting to focus on an individual's strengths rather than concentrating, as mental health professionals so often do, on their weaknesses.

In addition, the possibility remains that a certain amount of disdain exists amongst professionals working in generic health settings. Nightingale (2000), for example, identified widespread disdain for cervical screening for women with learning disabilities amongst general practitioners, identifying one local health authority policy document suggesting that women with 'mental subnormality' could be 'cancelled' from the cervical screening list. The possibility of different kinds of therapeutic disdain existing within the wider health system raises questions about the readiness of these services to cater for people with learning disabilities. Indeed, Rob Greig, who has the task of implementing the government's white paper on healthcare for people with learning disabilities, has emphasised the need to change the attitudes both of those working within learning disability services and those in generic healthcare services in order to successfully implement the policy (e.g. Greig, 2001).

# Areas for future research

This research has allowed the beginnings of an investigation into some of the factors that are important in the provision of psychological therapy to people with learning disabilities. There are, however, a number of areas where far more research is required.

One of the natural extensions to this research would be to develop the idea relating to competence. For example, theories such as the theory of reasoned action (Fishbein and Ajzen, 1975) grew out of much of Bandura's early work on self-efficacy. The theory suggests that people make decisions on the basis of a

reasoned consideration of the available information. It is suggested that both the importance of the desire to please people that matter to the individual (e.g. patients, colleagues, superiors), and what the individual believes, are those preferences that can influence the adoption of a particular behaviour (Fishbein & Ajzen, 1975). Therefore, in this model, the immediate determinant of behaviour is the person's intention to perform it. Intention summarises the individual's motivation to behave in a particular manner and indicates how hard the person is willing to try and how much time and effort he or she is prepared to expend in order to perform the behaviour (Ajzen, 1991). The determinants of people's intentions, in turn, are the favourability of their attitude towards the behaviour and the extent to which they perceive normative pressure to engage in the behaviour. It would be useful to investigate the relevance of models such as this in the case of clinicians working in learning disability services, and would allow some consideration of the way in which attitudes to service resources, competence, effectiveness, diagnostic overshadowing and the level of the client's disability inter-relate.

It is also important to look in more detail at the effect of the level of disability on the type of psychological therapy that clinicians offer, and to look in more detail at the way in which individual services assess, formulate and treat mental health problems in people with severe learning disabilities. It is important, therefore, to understand more about the application of psychological therapy to people with severe learning disabilities, and to develop a wider variety of effective treatments for this client group. Finally, it will be important to research the implications of the current government's proposal to shift the emphasis of healthcare for people with learning disabilities into generic services. Currently, little is understood about how well equipped such services are to support this client group, and indeed some of the evidence reviewed suggests that some of the attitudes of healthcare professionals in generic settings may be damaging to people with learning disabilities.

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## **Appendix 1: Letter to regional Special Interest Groups**

Jonathan Mason
UCL
Sub department of Clinical Health Psychology
Gower St.
London WC1E 6BT

Tel. 07980 008468

Dear «Title» «LastName»

I am a 2<sup>nd</sup> year trainee clinical psychologist at University College London, and am writing to you in relation to my doctoral thesis.

Briefly, I am planning a project which aims to examine some of the factors which may contribute to whether or not NHS clinical psychologists feel they can offer people with learning disabilities psychological therapy. I plan to do this by approaching all clinical psychologists who work in learning disabilities throughout the UK with a very brief questionnaire.

In consultation with Kay Hughes (chair of the national learning disability special interest group) I have decided that one of the most effective ways of approaching psychologists would be via the regional special interest groups. With this in mind, I am writing to you in your capacity as chair of a regional SpIG to ask whether you would be able to support my research by either:

- 1) providing me with contact details of those psychologists who are members of your regional group
- 2) or, if you have one, forwarding my questionnaire with your newsletter.

Obviously, the more psychologists I can include in my research the better! I will be providing pre-paid envelopes for participants to return their questionnaires. I should also say that the research has been approved by the UCL ethics committee.

It would be very useful for me if you were able to give me some idea of whether or not you feel you would be able to help me, so that I can plan my research more effectively. My contact details are at the top of this letter.

I look forward to hearing from you shortly.

Yours sincerely,

## **Appendix 2: Consent form**

#### Consent Form (CONFIDENTIAL)

'Factors effecting the provision of psychological therapy to people with learning disabilities in the NHS'.

#### Dear Participant,

Thank you for taking the time to consider taking part in this study. You do not have to take part if you do not want to. If you decide to take part you may withdraw at any time without having to give a reason. All proposals for research using human subjects are reviewed by an ethics committee before they can proceed. This proposal was reviewed by the Joint UCL/UCLH Committees on the Ethics of Human Research.

Please answer the questions below, and return this form with the questionnaire to: Jonathan Mason: UCL, Sub Dept. of Clinical Health Psychology, Gower Street, London WC1E 6BT

| Ø Have you read the information sheet about this study?   | YES | NO                  |
|---|-----|---------------------|
| Ø Were you given the opportunity to contact the researcher with an questions regarding this research? | •   | tional<br><b>NO</b> |
| Ø Have you received satisfactory answers to all your questions?                                       | YES | NO                  |
| Ø Have you received enough information about this study?  | YES | NO                  |
| Ø Do you understand that you are free to withdraw from this study                                     | :   |                     |
| 1) at any time  | YES | NO                  |
| 2) without giving a reason for withdrawing  | YES | NO                  |
| Ø Do you agree to take part in this study?  | YES | NO                  |
| Signed  | ·   |                     |

## **Appendix 3: Information letter**

CONFIDENTIAL

Jonathan Mason
UCL
Sub Dept. of Clinical Health Psychology
Gower Street
London WC1E 6BT

Dear participant,

Thank you for taking the time to read this letter. You may recently have received a similar letter and questionnaire from Roger Banks, who is one of the co-ordinators on a project organised by the joint learning disability and psychotherapy working party of the Royal College of Psychiatrists.

The questionnaire with this letter aims to develop some of the information gathered by the earlier questionnaire. The title of this project is 'Factors affecting the provision of psychological therapy to people with learning disabilities in the NHS'. We are interested in the types of psychological therapy services that are on offer to people with learning disabilities and what clinicians think about these.

The questionnaire is very brief, and should only take you a few minutes to complete. If you decide to take part, please return the completed questionnaire, along with the consent form, as soon as possible. If you have any questions regarding this research, then please do not hesitate to contact me at the address at the top of this letter.

Yours sincerely,



# Appendix 4: Ethics approval

# The University College London Hospitals

### The Joint UCL/UCLH Committees on the Ethics of Human Research

Committee Alpha Chairman: Professor A McLean

Please address all correspondence to:
Iwona Nowicka
Research & Development Directorate
UCLH NHS Trust
1st Floor, Vezey Strong Wing
112 Hampstead Road, London NW1 2LT
Tel. 020 7-380 9579 Rax 020 7-380 9937
e-mail: iwona.nowicka@uclh.org

Dr K Scior Lecturer in Learning Disabilities UCL Sub-Department of Clinical Health Psychology Gower Street

May 1, 2001

Dear Dr Scior

Study No:

01/0081 (Please quote in all correspondence)

Title:

Factors effecting the provision of psychological therapy to people with learning

disabilities in the NHS

Thank you very much for letting us see the above application which was reviewed by the Chairman and agreed by Chairman's Action. There are no objections on ethical grounds to this study going ahead

Please note that it is important that you notify the Committee of any adverse events or changes (name of investigator etc) relating to this project. You should also notify the Committee on completion of the project, or indeed if the project is abandoned. Please remember to quote the above number in any correspondence.

Yours sincerely

pp.

Mr R Rawles Vice-Chairman

/iin/Mav 1. 2001

University College London Hospitals is an NHS Trust incorporating The Eastman Dental Hospital, The Hospital for Tropical Diseases, The Middlesex Hospital, The National Hospital for Neurology & Neurosurgery, The United Elizabeth Garrett Anderson Hospital and Hospital for Women, Soho, and University College Hospital.

# **Appendix 5: Questionnaire**

Two versions of the questionnaire were produced:

- One including a clinical vignette describing a person with a learning disability.
- One including a clinical vignette describing a person with an IQ within the normal range.

Apart from the clinical vignettes, both versions of the questionnaire were identical.

Participants were randomly assigned to either of the two conditions (see methodology).

The complete questionnaire (normal range IQ version) is included overleaf, on p. 120. The different vignette (learning disability range IQ) is included on p. 126 for information.

# Questionnaire: Psychological Therapies with people with Learning Disabilities

| 1) G           | ender: M           | ale / Fem  | iale (pleas                         | se circle)  |   |
|----------------|--------------------|------------|-------------------------------------|-------------|---|
| 2) Jo          | b title:           |            | · · · · · · · · · · · · · · · · · · |             | <del></del>   |
| 3) W           | TE of po           | st         |                                     |             |   |
| 4) H           | ow many            | years ha   | ve you be                           | en qualifi  | ed for?   |
| 5) H           | ow many            | years / m  | onths hav                           | e you be    | en working in you current service?  |
| 6) H           | ow many            | psychiat   | rists are th                        | ere in yo   | ur service?   |
| 7) H           | ow many            | clinical p | osycholog                           | ists are th | ere in your service?  |
| 8) H           | ow many            | counsell   | ing psycho                          | ologists a  | re there in your service?   |
| 9) O           | n average          | , how ma   | any clinica                         | ıl psychol  | ogy trainees are there in your service?   |
| defir          | <u>iitely;</u> cii | rcle num   | ber                                 |             | nswer these questions: $I = \underline{not \ at \ all}$ , $5 = \underline{yes}$ , r therapy is in alleviating psychological distress? |
| 1              | 2                  | 3          | 4                                   | 5           |   |
| 11) I          | Oo you pe          | ersonally  | use it?                             |             | Yes / No (please circle)  |
| 12) I<br>distr |                    | ctive do y | ou think o                          | cognitive   | therapy / CBT is in alleviating psychological   |
| 1              | 2                  | 3          | 4                                   | 5           |   |
| 13) I          | Do you po          | ersonally  | use it?                             |             | Yes / No (please circle)  |
| 14) I<br>distr |                    | ctive do y | ou think p                          | osychody    | namic therapy it is in alleviating psychological  |
| 1              | 2                  | 3          | 4                                   | 5           |   |
| 15) I          | Oo you pe          | ersonally  | use it?                             |             | Yes / No (please circle)  |
| 16) I          | low effec          | ctive do y | ou think g                          | group the   | rapy is in alleviating psychological distress?  |
| 1              | 2                  | 3          | 4                                   |             |   |
| 17) I          | Do you pe          | ersonally  | use it?                             |             | Yes / No (please circle)  |

| 18) H           | low effec  | ctive do y     | ou think         | systemic the   | erapy is in all                       | eviating p      | sycholog            | ical distr          | ess?        |
|-----------------|------------|----------------|------------------|----------------|---------------------------------------|-----------------|---------------------|---------------------|-------------|
| 1               | 2          | 3              | 4                | 5              |                                       |                 |                     |                     |             |
| 19) D           | o you po   | ersonally      | y use it?        |                |                                       |                 | Yes                 | No (plea            | ase circle) |
| 20) H<br>distre |            | ctive do y     | ou think         | indirect wor   | k with carer                          | s is in alle    | eviating p          | sycholog            | ical        |
| 1               | 2          | 3              | 4                | 5              |                                       |                 |                     |                     |             |
| 21) D           | o you po   | ersonally      | y use it?        |                |                                       |                 | Yes                 | / No (ple           | ase circle) |
| Pleas           | se rate ho | ow <u>comp</u> | <u>etent</u> you | feel in using  | the following                         | g with yo       | ur curren           | ı <i>t client</i> g | roup:       |
| 22) B           | Sehaviou   | therapy        |                  |                | 23)                                   | Cognitive       | therapy /           | CBT                 |             |
| 1               | 2          | 3              | 4                | 5              | 1                                     | 2               | 3                   | 4                   | 5           |
| 24) P           | sychody    | namic the      | erapy            |                | 25)                                   | Group the       | erapy               |                     |             |
| 1               | 2          | 3              | 4                | 5              | 1                                     | 2               | 3                   | 4                   | 5           |
| 26) S           | ystemic    | therapy        |                  |                |                                       |                 |                     |                     |             |
| 1               | 2          | 3              | 4                | 5              |                                       |                 |                     |                     |             |
|                 |            |                |                  | a week of the  | e following ty                        | pes of psy      | vchologic           | al interv           | ention do   |
| 27) B           | ehaviou    | ral therap     | у                |                |                                       | <del></del>     |                     |                     |             |
| 28) C           | Cognitive  | therapy.       | / CBT            |                | · · · · · · · · · · · · · · · · · · · |                 |                     |                     |             |
| 29) P           | sychody    | namic th       | erapy            |                |                                       | <del></del>     |                     |                     |             |
| 30) G           | iroup the  | гару           |                  |                |                                       | <del></del>     |                     |                     |             |
| 31) S           | ystemic    | therapy        |                  | <u></u>        | · <del></del>                         |                 |                     |                     |             |
| To wh           | hat exten  | t do you       | agree wit        | th the followi | ng statements                         | (1 = <u>not</u> | <u>at all</u> , 5 = | <u>ves, def</u>     | initely)?   |

To what extent do you agree with the following statements (1 = not at all, 5 = yes, definitely): (circle number)

32) Behaviour-based therapies are usually more useful than 'psychological therapies' (in this case, direct contact with the client based around a talking therapy, such as cognitive therapy, psychodynamic therapy, systemic therapy) for people with learning disabilities.

|                   | ,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,, |                       |           |                           |   |
|-------------------|--|-----------------------|-----------|---------------------------|---|
| 1                 | 2                                      | 3                     | •         | -                         | ish!! I laamina diashiikisa assaa madalama aa                         |
|                   |  |                       |           | eip peopie<br>ormal intel | with mild learning disabilities overcome problems as                  |
| much              | as it can                              | norp tho              | oc with h | ormar mico                |   |
|                   |  |                       |           |                           |   |
| 1                 | 2                                      | 3                     | 4         | 5                         |   |
|                   |  |                       |           |                           | with moderate learning disabilities overcome normal intelligence.     |
| 1                 | 2                                      | 3                     | 4         | 5                         |   |
|                   |  |                       |           |                           | with severe learning disabilities overcome problems telligence.       |
| 1                 | 2                                      | 3                     | 4         |                           |   |
|                   |  |                       |           |                           | r in the successful treatment of people with <b>mild</b> al problems. |
| 1                 | 2                                      | 3                     | 4         | 5                         |   |
|                   |  |                       |           |                           | r in the successful treatment of people with moderate al problems.    |
| 1                 | 2                                      | 3                     | 4         | 5                         |   |
|                   |  |                       |           |                           | r in the successful treatment of people with severe al problems.      |
| 1                 | 2                                      | 3                     | 4         |                           |   |
| 39) Ps<br>disabil |  | ical thera            | py is moi | re useful th              | an behaviour therapies for people with mild learning                  |
| 1                 | 2                                      | 3                     | 4         | 5                         |   |
| 40) Ps            | ychologi<br>ng disabi                  | ical thera<br>lities. | py is moi | re useful th              | an behaviour therapies for people with moderate                       |
| 1                 | 2                                      | 3                     | 4         |                           |   |
|                   | ychologi<br>ng disabi                  |                       | py is moi | re useful th              | an behaviour therapies for people with severe                         |
|                   |  |                       |           |                           |   |

|   |   |                        | apy with pelligence.  |          | vith mild learning disabilities is harder to do than with   |
|---|---|------------------------|-----------------------|----------|---|
| 1 | 2 | 3                      | 4                     | 5        |   |
|   |   |                        | apy with pal intellig |          | vith moderate learning disabilities is harder to do than    |
| 1 | 2 | 3                      | 4                     | 5        |   |
|   |   |                        | apy with pelligence.  |          | vith severe learning disabilities is harder to do than with |
| 1 | 2 | 3                      | 4                     | 5        |   |
|   |   | l enough<br>disabiliti |                       | o succes | sfully undertake psychological therapy with people with     |
| 1 | 2 | 3                      | 4                     | 5        |   |
|   |   | l enough<br>rning disa |                       | o succes | sfully undertake psychological therapy with people with     |
| 1 | 2 | 3                      | 4                     |          |   |
|   |   | l enough<br>g disabil  |                       | o succes | sfully undertake psychological therapy with people with     |
| 1 | 2 | 3                      | 4                     | 5        |   |
|   |   |                        |                       |          |   |

Tom – a 19 year old man, is brought to an outpatient appointment by his sister

At interview, Tom is dirty and unkempt. According to his sister, he has not been eating or washing properly over the past 3 weeks. She tells you that Tom has been staying with her for the last week, and is reluctant to return home, where he lives by himself. Tom says that he feels 'down in the dumps' and 'angry all the time'. He says that he no longer enjoys being with his friends, who he says are all 'better than him'. He is restless, and says that he has not been able to go into work or go out with his friends recently. Tom's sister says that he has become highly irritable over the past week or so, and has shouted at her many times. She also says that, on one occasion, Tom got so angry he threw a cup of coffee at her.

Tom tells you that he did fine at school, and got 5 GCSE's. He went on to do a vocational qualification in Hotel Management, but had stopped going recently. His sister tells you that he had an IQ test when he started college, which said he had an IQ of 108.

| Que | stions             |                   |          |           |           |                             |            |
|-----|--------------------|-------------------|----------|-----------|-----------|-----------------------------|------------|
|     | se answ<br>iitely) | ve <b>r</b> the j | followir | ig ques   | stions al | oout Tom (1 = not likely, 7 | ' <b>=</b> |
| How | likely             | would y           | ou say   | it is tha | it Tom l  | as schizophrenia?           |            |
| 1   | 2                  | 3                 | 4        | 5         | 6         | 7                           |            |
| How | likely             | would y           | ou say   | it is tha | at Tom h  | as a drug problem?          |            |
| 1   | 2                  | 3                 | 4        | 5         | 6         |                             |            |
| How | likely             | would y           | ou say   | it is tha | ıt Tom l  | as Depression?              |            |
| 1   | 2                  | 3                 | 4        | 5         | 6         |                             |            |
| How | likely             | would y           | ou say   | it is tha | ıt Tom h  | as an anxiety disorder?     |            |
| 1   | 22                 | 3                 | 4        | 5         | 6         |                             |            |
| How | likely             | would y           | ou say   | it is tha | ıt Tom i  | s being bullied at work?    |            |
| 1   | 2                  | 3                 | 4        | 5         | 6         |                             |            |

| Does                        | Tom r                          | equire a                          | an admi                              | ssion?                             |  |  |
|-----------------------------|--------------------------------|-----------------------------------|--------------------------------------|------------------------------------|--|--|
| 1                           | 2                              | 3                                 | 4                                    | 5                                  | 6                                      |  |
| Woul                        | d you                          | conside                           | er a Men                             | ntal Hea                           | th Act                                 | assessment?  |
| 1                           | 2                              | 3                                 | 4                                    | 5                                  | 6                                      |  |
| Woul                        | d Tom                          | benefi                            | t from N                             | <b>Medicat</b>                     | ion?                                   |  |
|                             |                                |                                   | 4                                    |                                    |  | 7  |
|                             | <del>-</del>                   |                                   |                                      | <u> </u>                           |  | <del></del>  |
| Woul                        | d Tom                          | benefi                            | t from p                             | sycholo                            | ogical tl                              | herapy?  |
| 1                           | 2                              | 3                                 | 4                                    | 5                                  | 6                                      | 7  |
|                             |                                |                                   |                                      |                                    |  |  |
| partici<br>and ou<br>myself | pation i<br>r under<br>and app | n an inte<br>standing<br>oroximat | rview wo<br>of the tre<br>ely half a | uld help<br>eatments<br>in hour of | to signifi<br>offered to<br>f your tin | who have completed this questionnaire. Your cantly increase the usefulness of these results o service users. It would involve a visit by ne, which would be greatly appreciated.  in your details below and I will contact you in due course |
| Name_                       |                                |                                   | <del></del>                          |                                    |  | <del></del>  |
| Addres                      | —<br>ss of ser<br>—            | vice, incl                        | luding tel                           | ephone n                           | number ai                              | nd email   |
|                             |                                |                                   |                                      |                                    |  |  |
| Best da                     | ay to coi                      | ntact                             | <del></del>                          |                                    |  |  |

#### Learning disability IQ vignette

Tom – a 19-year-old man, is brought to an outpatient appointment by his sister.

At interview, Tom is dirty and unkempt. According to his sister, he has not been eating or washing properly over the past 3 weeks. She tells you that Tom has been staying with her for the last week, and is reluctant to return home, where he lives by himself. Tom says that he feels 'down in the dumps' and 'angry all the time'. He says that he no longer enjoys being with his friends, who he says are all 'better than him'. He is restless, and says that he has not been able to go into work or go out with his friends recently. Tom's sister says that he has become highly irritable over the past week or so, and has shouted at her many times. She also says that, on one occasion, Tom got so angry he threw a cup of coffee at her.

Tom tells you that he left school at 16. He says that he went to a 'special school', but did not get any qualifications. He lives with 2 friends in a flat, and has help from a support worker who comes to see them every day. Tom has a job in McDonalds, which he says he used to enjoy but has not been for 2 weeks. Tom's sister tells you that she thinks he has a 'moderate learning disability', and shows you a letter from a psychologist which indicates that he had an IQ of 58 when tested at age 16.