

**The experiences of high intensity therapists delivering cognitive behavioural therapy to individuals with learning disabilities in IAPT services.**

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## **ABSTRACT**

Recent legislation has set the way for a new policy shift emphasising the need for increased access to mainstream services for people with learning disabilities. Services are now required to demonstrate how they are making 'reasonable adjustments' in order to facilitate equal access.

The Improving Access to Psychological Therapy programme (IAPT) is a government initiative aiming to increase access to psychological therapies to adults experiencing mental health problems. They have produced practice guidelines indicating how IAPT services should be flexible in responding to the needs of individuals with learning disabilities. IAPT offer interventions based predominately on cognitive behavioural models, and whilst there is a growing evidence-base for the use of cognitive behavioural therapy (CBT) with people with learning disabilities, it is unclear how effective CBT is for this group when delivered within IAPT.

Ten high intensity therapists, who had delivered CBT to at least one person with learning disabilities in IAPT, took part in semi-structured interviews regarding their experiences. Interviews were transcribed verbatim and analysed using thematic analysis.

Findings suggested that therapists felt uncertain about how to modify CBT for people with learning disabilities, and they identified a need for improved training opportunities and specialist supervision to support them in their roles. On a systemic level, it appeared that the rigidity of the IAPT model often provided a poor fit with people with learning disabilities. Consequently, therapists faced additional challenges when attempting to adapt CBT and make necessary reasonable adjustments for this service user population. Implications of the findings for future research, policy and practice are considered. A critical review of this study is provided in the final part of this thesis.

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## TABLE OF CONTENTS

<b>1. INTRODUCTION.....</b>	<b>1</b>
1.1 Overview of the research .....	1
1.2 Learning disabilities definition, diagnosis and prevalence .....	1
1.2.1 Defining learning disabilities .....	1
1.2.2 Diagnosis of learning disabilities.....	1
1.2.3 Prevalence rates of people with learning disabilities.....	2
1.3 The mental health needs of people with learning disabilities.....	3
1.3.1 Prevalence rates of mental health problems in people with learning disabilities .....	3
1.3.2 Historical approaches to treatment and delivery of mental health services ...	4
1.3.3 Current UK legislation and policy.....	5
1.4 The Improving Access to Psychological Therapies (IAPT) programme for people with learning disabilities.....	6
1.4.1 An overview of the IAPT programme .....	6
1.4.1.1 NICE guidelines .....	6
1.4.1.2 Cognitive behaviour therapy.....	7
1.4.1.3 A stepped care approach .....	8
1.4.1.4 IAPT high intensity therapists.....	8
1.4.1.5 IAPT minimum data set.....	9
1.4.2 The IAPT Learning Disabilities Positive Practice Guide.....	11
1.5 Literature review.....	12
1.5.1 Search strategy.....	12
1.5.2 Evidence for IAPT for people with learning disabilities .....	12
1.6 CBT for people with learning disabilities.....	15
1.6.1 The evidence-base for CBT for people with learning disabilities.....	15
1.6.2 The suitability of people with learning disabilities for CBT .....	18
1.6.3 Modifications and adaptations to CBT for people with learning disabilities ..	20
1.6.3.1 The therapeutic relationship.....	22
1.6.4 Therapist confidence in delivering CBT to people with learning disabilities .	24
1. 7. Rationale and aims of the current study .....	27
1.7.1 Research Questions .....	28
<b>2. METHODOLOGY.....</b>	<b>29</b>

2.1 Epistemological position .....	29
2.2 Rationale for a choice of qualitative method.....	29
2.3 Rationale for thematic analysis .....	30
2.4 Researcher reflexivity .....	32
2.5 Participants .....	33
2.5.1 Recruitment .....	33
2.5.2 Sample .....	33
2.6 Data collection.....	34
2.6.1 Therapy Confidence Scale-Intellectual Disabilities (TCS-ID) administration	34
2.6.2 Interview process.....	35
2.6.3 Measures .....	35
2.6.3.1 <i>The Therapy Confidence Scale-Intellectual Disabilities (TCS-ID)</i> .....	35
2.6.4 Materials .....	36
2.6.4.1 <i>Digital recorder</i> .....	36
2.6.4.2 <i>Interview schedule</i> .....	37
2.7 Ethical considerations .....	38
2.7.1 Ethical approval .....	38
2.7.2 Consent and anonymity .....	38
2.8 Data Analysis .....	39
2.8.1 Transcription .....	39
2.8.2 The process of thematic analysis.....	39
<b>3. RESULTS .....</b>	<b>42</b>
3.1 Therapy Confidence Scale-Intellectual Disabilities (TCS-ID) scores for participants.....	42
3.2 Themes .....	43
3.2.1 Theme one: LD not on IAPT agenda .....	44
3.2.1.1 <i>Sub-theme: Tokenistic commitment to LD in IAPT</i> .....	44
3.2.1.2 <i>Sub-theme: Inadequacy of training</i> .....	47
3.2.1.3 <i>Sub-theme: The importance of supervision</i> .....	49
3.2.2 Theme two: Fit with short-term recovery model .....	50
3.2.2.1 <i>Sub-theme: Conflicting agendas of therapy</i> .....	51
3.2.2.2 <i>Sub-theme: Ability to fit with recovery expectations</i> .....	52
3.2.2.3 <i>Sub-theme: Working within the constraints of the model</i> .....	53
3.2.3 Theme three: Service short-comings .....	56

3.2.3.1 Sub-theme: Failure to adjust expectations placed on therapist .....	57
3.2.3.2 Sub-theme: Service failure to make reasonable adjustments .....	59
3.2.3.3 Sub-theme: Ethical dilemmas facing therapists.....	62
3.2.4 Theme four: Uncertainty about the work.....	63
3.2.4.1 Sub-theme: Increased complexity of the work.....	64
3.2.4.2 Sub-theme: Feeling out of one's depth .....	65
3.2.4.3 Sub-theme: The appropriateness of IAPT for people with LD .....	68
<b>4. DISCUSSION.....</b>	<b>70</b>
4.1 Summary of findings.....	70
4.2 Theoretical implications.....	71
4.2.1 Recent developments within the literature .....	71
4.2.2 The modification of CBT within IAPT .....	71
4.2.3 Policy implementation.....	77
4.2.4 Evolving IAPT services .....	81
4.3 Implications and recommendations .....	83
4.3.1 Implications for practice and policy .....	83
4.3.2 Implications for further research .....	85
4.3.3 Dissemination .....	86
4.4 Critical evaluation of the research .....	87
4.4.1 Sampling and generalisation of findings .....	89
4.4.2 Critical evaluation of the analysis process .....	91
4.4.3 Researcher reflexivity .....	92
4.5 Conclusion .....	94
<b>5. REFERENCES.....</b>	<b>96</b>
<b>6. APPENDICES.....</b>	<b>120</b>
Appendix 1: Literature search details .....	120
Appendix 2: Reflective journal extracts .....	128
Appendix 2.1: Reflective journal extract during recruitment phase .....	128
Appendix 2.2: Reflective journal extract following pilot interview .....	128
Appendix 2.3: Reflective journal extract following first interview .....	129
Appendix 2.4: Reflective journal extract following last interview .....	130
Appendix 2.5: Reflective journal extract during analysis.....	131
Appendix 4: Email sent to IAPT staff teams .....	135

Appendix 5: Information covered during presentations to IAPT service team meetings.....	136
Appendix 6: Participant Consent form .....	138
Appendix 7: Interview schedule.....	140
Appendix 8: UEL ethical approval .....	141
Appendix 9: Email documentation confirming fulfilment of UEL ethical amendments .....	143
Appendix 10: NHS R&D approval letters.....	144
Appendix 11: Transcription conventions used.....	148
Appendix 12: Extract of annotated transcript.....	149
Appendix 13: Description of analytical process .....	152
Appendix 13.1: Identification of initial codes .....	152
Appendix 13.2: Examples of coded data extracts .....	154
Appendix 13.3: Identification of potential higher-order themes .....	156
Appendix 13.4: Thematic Map 1 .....	158
Appendix 13.5: Thematic Map 2 (Final) .....	159

## TABLE OF FIGURES

Figure 1 Thematic Map of themes relating to therapists' experiences of delivering CBT to people with learning disabilities (LD).....	43
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## TABLE OF TABLES

Table 1: Participant TCS-ID scores and professional experience.....	42
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# **1. INTRODUCTION**

## **1.1 Overview of the research**

In this chapter, the delivery of cognitive behavioural therapy (CBT) for people with learning disabilities within the Improving Access to Psychological Therapies (IAPT) programme will be explored, with a particular focus on the role of the high intensity therapist. Existing literature regarding the accessibility and effectiveness of the IAPT programme for people with learning disabilities will be discussed, as well as literature concerning key client and therapist factors that may affect the delivery of CBT as part of IAPT. The chapter will conclude with the rationale, aims and research questions of the present study.

## **1.2 Learning disabilities definition, diagnosis and prevalence**

### 1.2.1 Defining learning disabilities

A number of terms are used worldwide to describe people who have significant cognitive impairments which impact on their intellectual and adaptive functioning. The most commonly used terms within the UK include 'learning disabilities' and 'intellectual disabilities'. Internationally, labels such as 'mental retardation', 'mental handicap', and 'developmental disabilities' are also used. The term 'learning disabilities' will be used in this thesis to refer to the population this research relates to as this is the term used by the IAPT programme, as well as other health and social care organisations in England.

### 1.2.2 Diagnosis of learning disabilities

The Diagnostic and Statistical Manual of Mental Disorders; DSM-5 (American Psychiatric Association; APA, 2013) and the International Classification of Diseases Classification of Mental and Behavioural Disorders; ICD-10 (World Health



Organisation; WHO, 1992) are the current classification systems used to clinically diagnose learning disabilities. Both systems define learning disabilities as including significant impairment of intellectual functioning (an intelligence quotient [IQ] score of below 70), alongside significant impairment of adaptive functioning in two or more areas of daily functioning, and the impairments being present before 18 years of age (British Psychological Society; BPS, 2001). Learning disabilities are understood as being on a continuum, indicating the severity of a person's disability: referred to as mild, moderate, severe and profound learning disabilities.

The conceptualisation of learning disabilities is underpinned by a medical framework in which a person's associated difficulties are considered to result directly from their individual impairments. However, some have expressed criticism that this model, in its emphasis on how people differ from socially-determined norms (Borsay, 2005), promotes the devaluation of people as citizens on the basis of their disability status (Scullion, 2009). The social model of disability (Oliver, 1990) challenges the dominant medical framework, and acknowledges social causes of impairments. Here, disability is moved out of the private, medical sphere into the political and public realm and the collective contribution towards oppression is acknowledged (Scullion, 2009). Rapley (2004) suggested that the use of 'objective' scientific methods, and the medical model, has led to the view of 'learning disabilities' as a homogenous disorder. However, he highlighted that the label is a social construction which in reality is associated with heterogeneity and diversity. Furthermore, the current diagnostic category of learning disabilities does not provide a qualitative distinction between people who meet diagnostic criteria and those whose IQ or adaptive functioning falls below cut-off criteria (Dagnan, Jahoda & Kilbane, 2013).

### 1.2.3 Prevalence rates of people with learning disabilities

Reported prevalence rates of learning disabilities vary due to methodological difficulties associated with research. However, epidemiological studies suggest that approximately 2% of the general adult population within the UK have learning disabilities, although of these only 20% are thought to be known to specialist social care learning disability services (Public Health England, 2014). This indicates that a

large proportion of adults with learning disabilities have not received a diagnosis, and may not be accessing specialist services.

### **1.3 The mental health needs of people with learning disabilities**

#### **1.3.1 Prevalence rates of mental health problems in people with learning disabilities**

People with learning disabilities often experience high levels of negative life events, associated with an increased risk of developing mental health problems (Emerson & Baines, 2011). Due to the different diagnostic criteria and assessment methods used by epidemiological studies, accurate prevalence rates of mental health problems are hard to determine for people with learning disabilities. However, population-based studies using screening instruments suggest prevalence rates between 20 to 40 per cent (Taylor & Knapp, 2013), with vulnerability to mental health problems at least similar or higher compared to people without learning disabilities (Cooper, Smiley, Morrison, Williamson & Allan, 2007). High rates of anxiety and depression have also been reported (Hatton & Taylor, 2010). However, difficulties in recognising psychological distress in individuals who have cognitive and communication impairments (Rose, Obrien & Rose, 2007), and 'diagnostic overshadowing' (Reiss, Levitan & Szyszko, 1982), whereby psychiatric symptoms are misattributed to a person's learning disabilities, may result in psychological needs being under-reported (Cooper et al., 2007) and unmet (Stenfert Kroese, Rose, Heer & O'Brien, 2013). This continues to be a barrier for people with learning disabilities accessing appropriate support (Donner, Mutter & Scior, 2010; Rose et al., 2007).

Anxiety and depression are diagnosed using the DSM-5 (APA, 2013) and the ICD-10 (WHO, 1992). Different types of 'anxiety disorders' are distinguished, although symptoms may include feelings of panic and fear, uncontrollable obsessive thoughts, intrusive memories and physical symptoms (WHO, 1992). Depression is conceptualised as a mood disorder, and associated symptoms include reduced energy, interest and pleasure in normal activities, disturbances in appetite, weight or sleep as well as concentration difficulties (WHO, 1992). However, high levels of symptom overlap and comorbidity between anxiety and depression have been

reported (Löwe et al., 2008), and Mollon (2009) highlights how clients accessing clinical services frequently present with multiple conditions. Consequently, the conceptualisation of anxiety and depression as discrete disorders may be a false dichotomy. This may be of particular relevance to people with learning disabilities, who may present with high levels of comorbidity (Lindsay et al., 2015).

The presentation of mental health problems is thought to differ in people with learning disabilities, compared to the general population (Hassiotis et al., 2012). 'Atypical' manifestations of mental distress, including 'challenging behaviour' may be presented along with increased somatic symptoms (Azam, Sinai & Hassiotis, 2009). Hatton and Taylor (2013) have questioned the use of categorical systems used for the general population for people with learning disabilities, highlighting difficulties in applying systems which assume a usual level of functioning. The Diagnostic Manual for Intellectual Disabilities (DM-ID) (Fletcher, Loschen, Stavrakaki & First, 2007) offers discussion of issues related to diagnosis in people with learning disabilities and provides modified diagnostic criteria for use with individuals with learning disabilities who present with mental health problems.

### 1.3.2 Historical approaches to treatment and delivery of mental health services

Historically, the emotional lives of people with learning disabilities have been overlooked (Sinason, 2000), and their access to psychological treatment poor (Willner, 2005). People were often denied access to talking therapies on the basis of having learning disabilities. Subsequently, this population has frequently been excluded from research, limiting the development of an evidence-base on effective psychological interventions (Brown, Duff, Karatzias & Horsburgh, 2011).

Traditionally, interventions have predominately relied upon behavioural and pharmacological treatments (Arthur, 2003; Willner, 2005). However, it is suggested that these approaches have often neglected the client's psychological needs (Stenfert Kroese, 1998), and have instead met the needs of others (Waitman & Reynolds, 1992). Despite earlier assumptions, recent years have seen a shift in attitudes towards the delivery of talking therapies, including CBT, to people with

learning disabilities. Whilst previously doubted, it is now generally accepted that people with learning disabilities experience stable cognitions (Lindsay, Michie, Baty, Smith & Miller, 1994), which are influential in the development and perpetuation of emotional distress (McGillivray & McCabe, 2010). Accordingly, there has been a developing argument that CBT can be effective for this population.

Currently within the UK, most health care services for people with learning disabilities are provided by National Health Service (NHS) specialist community learning disability teams. Teams are multi-disciplinary, and often include occupational therapists, psychiatrists, nurses and psychologists.

### 1.3.3 Current UK legislation and policy

Current legislation and policy stipulate that people with learning disabilities, wherever possible, should be able to access mainstream health services. The government white paper Valuing People (Department of Health; DoH, 2001) outlined a policy objective to provide people with learning disabilities with equitable access to evidence-based healthcare, designed around their individual needs. Valuing People Now (DoH, 2009a) provided a three year strategy plan to reinforce these values and objectives, highlighting that progress in achieving original objectives had been slow. The Equality Act (2010) consolidates previous legislation and places responsibility upon services to make 'reasonable adjustments' to facilitate equal access to services.

The Green Light Tool Kit (Foundation for People with Learning Disabilities; FPLD, 2004) provides an auditing tool for services to evaluate how well they are adhering to standards outlined by the National Service Framework (NSF) for mental health (DoH, 1999) for people with learning disabilities. The tool offers a traffic light system, with green demonstrating good adherence to standards. It identifies gaps in service provision for people with learning disabilities, and highlight areas for service development.

The Monitor Compliance Framework 2013/ 2014 (Monitor, 2013) was introduced in 2013 and outlines criteria for meeting the needs of people with learning disabilities which Foundation Trusts in England are required to meet. Criteria are based on recommendations outlined in 'Healthcare for All' (Michael, 2008), and Trusts are required to demonstrate how they make reasonable adjustments to care pathways for people with learning disabilities accessing their services.

## **1.4 The Improving Access to Psychological Therapies (IAPT) programme for people with learning disabilities**

### 1.4.1 An overview of the IAPT programme

Improving Access to Psychological Therapies is a large scale national health programme, which aims to increase the accessibility of evidence-based psychological therapies for adults experiencing common mental health problems, namely mild to moderate depression or anxiety disorders. The programme was launched in 2008 and was underpinned by clinical and economic agendas. It considered that the increased availability of CBT, recommended for the treatment of depression and anxiety disorders (National Institute of Clinical Excellence; NICE, 2009; NICE, 2011), would result in reduced public costs and increased workforce productivity (The Layard Report; Layard, 2006). Typically, IAPT is accessed through general practitioner (GP) or self-referrals. Currently, the dominant therapeutic model endorsed by IAPT is CBT although other evidence-based interventions, including counselling and interpersonal psychotherapy, are now offered within some IAPT services.

#### 1.4.1.1 NICE guidelines

Psychological interventions offered within IAPT are determined by guidelines produced by NICE, an independent organisation providing recommendations on evidence-based clinical treatments. The guidelines relate to specific diagnostic categories such as depression (NICE, 2009), generalised anxiety disorder and panic disorder (NICE, 2011), obsessive compulsive disorder (NICE, 2005), social anxiety

(NICE, 2013) and post-traumatic stress disorder (NICE, 2005). For all of these disorders, CBT is recommended as a primary intervention alone, or alongside pharmacological treatment. Guidelines are based upon research studies which have demonstrated effectiveness over other types of interventions, with randomised controlled trials (RCTs) regarded as the most rigorous of research. NICE guidelines for depression (NICE, 2009) and anxiety (NICE, 2011) make reference to adjustments that may be required to both assessment and intervention for people with learning disabilities. These include using validated measures and adjusting the method of delivery or duration of the intervention.

#### 1.4.1.2 Cognitive behaviour therapy

CBT may be described as a time-limited, problem-orientated structured therapy. Central to the model is the assumption that 'dysfunctional thinking' can cause and maintain negative emotions and maladaptive behaviours (Beck, Rush, Shaw & Emery, 1979). Interventions are typically based upon disorder specific protocols and involve the identification of 'dysfunctional' cognitions, and empirical examination of their validity, using a range of cognitive and behavioural techniques. The specific CBT techniques utilised within therapy are weighted differently, dependent on the specific 'problem' being treated (Otte, 2011). However, they generally include a multitude of techniques including 'Socratic dialogues' (a questioning process encouraging self-reflection and problem solving), behavioural experiments, psycho-education and self-monitoring (Gilbert, 2009). The model places emphasis on the importance of a collaborative relationship between the therapist and client (Padesky, 1993), who is encouraged to actively participate in cognitive and behavioural activities (Beck, 1995).

Despite its wide application, a number of critiques have been expressed against CBT, specifically regarding its conceptualisation of mental distress. The CBT model is considered to place the location of distress and dysfunction within the individual i.e. their thoughts and behaviours (Boyle, 2014; Moloney & Kelly, 2004). Whilst contextual factors may be included within formulations, their impact is thought to be obscured and minimised (Boyle, 2011). This may be of particular importance to people with learning disabilities, who often experience high levels of social

inequalities and adversities (Emerson & Baines, 2011), associated with an increased risk of mental health problems (e.g. Fryers, Melzer & Jenkins, 2003). Based upon these arguments, the IAPT programme has been criticised for promoting a simplified conceptualisation of mental distress and subsequent treatment, rather than attending to social inequalities (Marzillier & Hall, 2009). Emerson (2011) suggests that inequalities, including those in mental health, will only begin to reduce when interventions address social causes of distress instead of focusing on individual therapy. In addition, Gerry and Crabtree (2013) caution the use of CBT with some individuals with learning disabilities, suggesting that certain techniques and questioning styles may reinforce feelings of incompetence and inability.

#### 1.4.1.3 A stepped care approach

A central tenet of IAPT is the delivery of timely and 'least restrictive' interventions to achieve maximum gain, and it operates using a stepped-care model (Bower & Gilbody, 2005; DoH, 2008a). In IAPT, step 1 of the model represents the acknowledgment of a mental health problem. Step 2 involves the delivery of 'low intensity' interventions to individuals experiencing mild to moderate psychological 'disorders', as indicated by a reviewing system, based on the minimum data set (MDS). Interventions at this step are typically delivered by psychological well-being practitioners; PWPs (formerly known as low-intensity therapists) and can involve a variety of formats, including computerised CBT, guided self-help, behavioural activation or psycho-educational groups (DoH, 2008a). Step 3 interventions are delivered by high intensity therapists and involve more individualised interventions over a longer treatment period to individuals displaying more 'severe' symptoms (DoH, 2008a).

#### 1.4.1.4 IAPT high intensity therapists

Qualification as a high intensity therapist is achieved through the completion of a one-year post-graduate diploma, whilst undertaking supervised clinical practice. High intensity trainees come from a range of backgrounds, including clinical psychology, psychotherapy, counselling, nursing and experienced graduate mental health workers (DoH, 2008b). Whilst no recent data are available, a 2009 IAPT report

(Aldridge & Duffy, 2009) indicated regional variance in the professional backgrounds of high intensity therapists, with clinical psychologists making up a much larger proportion of the high intensity workforce in London IAPT services when compared to all other regions. This may have implications on the skills and competencies of individual IAPT workforces.

The high intensity therapist training is underpinned by a cognitive behavioural theoretical framework, and is delivered in accordance with the British Association of Behavioural and Cognitive Psychotherapies (BABCP) guidelines for good practice. The course curriculum includes three modules: fundamentals of CBT, CBT for anxiety disorders and CBT for depression (DoH, 2008b). A CBT competence framework (Roth & Pilling, 2007) is used to assess trainees on specific and general learning outcomes.

IAPT recognises the need for a workforce competent in working with people with learning disabilities (DoH, 2009b; 2013). However, it is noticeable that whilst the high intensity curriculum makes reference to trainee competency surrounding adaptation of CBT for people from diverse cultural backgrounds, there is no specific mention of adapting CBT for people with learning disabilities.

#### 1.4.1.5 IAPT minimum data set

All IAPT services are required to collect outcome and patient satisfaction measures (DoH, 2012) which are referred to as the National Minimum Data Set (IAPT, 2011). Clients' clinical, work and social functioning are assessed at the point of initial assessment and at subsequent therapy sessions to ascertain treatment effectiveness. The data are recorded centrally, and used by local and national commissioners to evaluate service performance and to commission future services. The data set includes the Patient Health Questionnaire (PHQ-9), the Generalized Anxiety Disorder 7-item scale (GAD-7), and the Work and Social Adjustment Scale (WSAS) (see below). Cut-off scores for each measure are specified to indicate clinical severity and categorise 'recovery'; when a client's score falls below a certain threshold following treatment. National IAPT targets state that 50% of those entering



treatment within IAPT should reach 'recovery' status at the point of discharge from treatment (DoH, 2012).

The PHQ-9 (Kroenke, Spitzer & Williams, 2001) is a 9-item self-administered questionnaire, reflecting the diagnostic criteria for major depressive disorder in the Diagnostic and Statistical Manual Fourth Edition; DSM-IV (APA, 2000). Respondents are asked to rate their symptoms over the past two weeks, on a three-point Likert scale ranging from "not at all" to "nearly every day". Scores range from zero (no depression) to 27 (severe depression), with a cut-off of 10 or above. Its developers report good psychometric properties, including Cronbach's  $\alpha = 0.89$ , test-retest  $\alpha = 0.84$  (Kroenke et al., 2001). Other research has similarly attested to the psychometric properties of the PHQ-9 (Titov et al., 2011).

The GAD-7 (Spitzer, Kroenke, Williams & Lowe, 2006) is a 7-item self-administered questionnaire designed to identify and measure anxiety, as defined by DSM-IV (APA, 2000). Items are rated for the past two weeks using a four-point Likert scale ranging from "not at all" to "nearly every day". Scores range from zero ('no anxiety') to 21 ('severe anxiety'). As with the PHQ-9, it offers a cut-off point (of 8 or above) as a means to tentatively diagnose clinical anxiety and a severity score which treatment can be monitored upon (Löwe et al., 2008). Its developers report good internal consistency (Cronbach's  $\alpha = .92$ ) and good test-retest reliability (intraclass correlation = 0.83).

The WSAS (Mundt, Marks, Shear & Greist, 2002) is a 5-item self-report scale designed to measure work and social functioning. Items are rated using an eight-point Likert scale and scores range from 0 ('no impairment') to 8 ('very severe'). Total score severity bands are offered to indicate level of severity, ranging from "subclinical impairment" (0-10) to "severe impairment" (30+). Its developers report good internal consistency (Cronbach's  $\alpha = .70$  to  $.94$ ) and test-retest reliability (intraclass correlation = 0.73).

None of the above measures have been standardised for people with learning disabilities but appear to be used with this population in IAPT services (e.g. Radcliffe, O'Connor, Pollard & Cooposamy, 2011). However, one example of an

IAPT service using alternative measures validated for people with learning disabilities has been reported (Kirk, Sehmi, Hazeldine, Palmer & Ruddle, 2014), although potential financial implications of not administering the MDS to record outcomes was acknowledged. Furthermore, latest figures indicate only 7% of people with learning disabilities known to services are in any form of paid employment (Public Health England, 2014). Therefore, the way successful interventions are measured, including IAPT's emphasis on returning people to work, may not be as relevant for people with learning disabilities.

#### 1.4.2 The IAPT Learning Disabilities Positive Practice Guide

Equitable access to services is highlighted as a key target of the IAPT programme. A series of 'positive practice guides' outlining best practice guidance for the commissioning and delivery of services for specific populations, including people with learning disabilities, have been developed by 'special interest groups' consisting of 'experts' in each area.

The 'IAPT Learning Disabilities Positive Practice Guide' (DoH, 2009b), outlined a number of recommendations for services in ensuring their accessibility for people with learning disabilities. These included adapting assessment and intervention materials, offering more flexibility regarding service delivery and encouraging collaborative working with local community learning disability teams. However, whilst providing services with areas to consider, the guidance has received criticism for lacking clarity and direction regarding how to make the adaptations (Dodd, Joyce, Nixon, Jennison & Heneage, 2011). The practice guide has been recently updated (DoH, 2013), although does not appear to provide further direction regarding the implementation of adaptations. The document notes further upcoming updates to the publication, in collaboration with the Foundation for People with Learning Disabilities.

## **1.5 Literature review**

### **1.5.1 Search strategy**

The literature pertaining to the IAPT programme for people with learning disabilities was reviewed to set the context for the empirical work in this thesis. The following questions guided the review:

- (1) How well are IAPT services meeting the needs of people with learning disabilities?
- (2) Given that CBT has been the main model employed in IAPT to date, what evidence is there regarding key client and therapist factors that may affect the delivery of CBT as part of IAPT, namely:
  - (a) The evidence for CBT for people with learning disabilities
  - (b) The suitability of people with learning disabilities for CBT;
  - (c) Adaptations required to CBT in order to make the approach accessible for people with learning disabilities;
  - (d) Therapist confidence in delivering CBT to people with learning disabilities.

A literature search was conducted using PsycINFO, PsychARTICLES, CINAHL Plus and Scopus using a range of search terms for IAPT, CBT, people with learning disabilities and therapist confidence between January 1980 and September 2014. Google Scholar and grey literature including conference presentations and unpublished work were searched using the terms to find additional relevant articles. See Appendix 1 for further detail on the searches conducted. The following provides a narrative account of the literature identified.

### **1.5.2 Evidence for IAPT for people with learning disabilities**

Evidence for IAPT psychological therapies for people with learning disabilities currently relies on practice-based evidence rather than experimental designs. Whilst all IAPT services are required to adhere to national governance standards and policies, currently a national care pathway for people with learning disabilities

entering IAPT does not exist. As independently operated services they can vary significantly in eligibility criteria and the types of interventions they offer. The initial IAPT data system did not include a learning disabilities category and Leyin (2011) highlighted how this has resulted in a lack of clarity regarding the uptake of IAPT services by this population.

A number of local initiatives to increase the accessibility of IAPT for people with learning disabilities are reported in the literature, indicating examples of joint working between local IAPT and learning disability specialist teams. However, there appears variability across services regarding commitment towards such initiatives. Leyin (2011) noted concern that access to one IAPT service required completion of a complex administration system, unlikely to be accessible to people with learning disabilities.

Reported initiatives have included the development of care pathways for people with learning disabilities entering IAPT and adjusting assessment materials (Radcliffe et al., 2011) and the delivery of specialist training and supervision for IAPT staff (Dagnan, 2013; Dagnan, Masson, Cavagin, Thwaites & Hatton, 2014; Heneage, Dhanjal & Morris, 2009; Taylor & Harrison, 2013). Provision of specialist supervision to IAPT staff from learning disability clinicians has also been described, identified as a key contributor to delivery of effective service for people with learning disabilities (Kirk et al., 2014). Kirk et al. (2014) reported on the joint delivery of a CBT anxiety group for people with learning disabilities within IAPT, with a local learning disability team. Post-group analysis indicated no significant reduction in clients' anxiety, although the feasibility of group interventions for people with learning disabilities in IAPT was suggested. However, the authors highlighted the extra demands the group placed on time and resources, and questioned the cost-effectiveness and sustainability of future groups in a high volume IAPT service. The appointment of a single IAPT clinician to act as a 'learning disability expert' has also been described (Salmon et al., 2013), although staff-turnover was identified as potential barrier to this initiative. One IAPT service (Cumbria First-steps) has reported significant service developments, including adapted care pathways, interventions and session materials, provision of specialist training for IAPT staff and involving carers within therapy (Dagnan, 2013). Analysis of Cumbria First-steps IAPT service data indicated

effectiveness of IAPT for people with learning disabilities, although numbers accessing the service were lower than expected based on local demographic data (Hatton, Dagnan, Thwaites, Mason & Cavagin, 2013).

Whilst these are all indications of positive service developments, rather than being a national initiative, the inclusion of people with learning disabilities in IAPT appears dependent on the values and commitment of local IAPT services and commissioners (Leyin, 2011). The Joint Commissioning Panel for Mental Health (2013) makes reference to anecdotal reports suggesting that IAPT services may be excluding people with learning disabilities, which would place services in breach of equalities legislation. IAPT services are high-volume services, have a significant number of outcome measures to administer and have high performance targets to meet, all of which may present challenges to delivering interventions to people with learning disabilities (Thwaites, 2013). In a qualitative analysis of the views of mainstream and specialist learning disability staff (N=29), Rose et al. (2007) reported staff felt heavy workloads, time constraints and lack of resources presented challenges in meeting the needs of people with learning disabilities in mainstream services. In addition, therapists' attitude towards working with people with learning disabilities has also been suggested to influence therapy outcomes (Beail & Jahoda, 2012), and to present potential barriers in developing accessible services (Royal College of Psychiatrists, 2004). Staff working in mainstream services may not consider working with people with learning disabilities to be part of their role, and feel inadequately trained to do so (Rose et al., 2007). This may have particular relevance to staff expected to provide therapy to people with learning disabilities in busy high-volume IAPT services.

Additional initiatives aimed at increasing the accessibility of IAPT services for people with learning disabilities have included the development of an IAPT advisory group by the Foundation for People with Learning Disabilities. The group facilitate 'action learning sets' aimed at encouraging joint working between local services and provide a small number of training workshops on the development of IAPT services for people with learning disabilities (IAPT website). However, the accessibility and effectiveness of IAPT services for people with learning disabilities remains unclear. There have been no systematic evaluations of CBT delivered to people with learning

disabilities within IAPT and Beail (2011) has questioned whether IAPT has had any impact at all on this population.

## **1.6 CBT for people with learning disabilities**

The effectiveness of CBT for the treatment of a wide range of mental health problems within the general population has been well recognised (Roth & Fonagy, 1996), including anxiety and depression (Butler, Chapman, Forman & Beck, 2006). However, evidence for the specific mechanisms of change within CBT appears inconclusive (e.g. Oei, McAlinden & Cruwys, 2014). This indicates a need to dismantle studies to develop theoretical understanding regarding effective components of CBT packages.

### 1.6.1 The evidence-base for CBT for people with learning disabilities

Compared to the general population, the development and evaluation of CBT for people with learning disabilities is significantly less advanced, although an increasing body of literature indicates its effectiveness for a range of psychological difficulties. Vereenoghe and Langdon (2013), in a meta-analysis of 14 psychotherapy intervention studies reported favourable outcomes for CBT for the treatment of anger and depression for people with learning disabilities. However, the evidence-base is still considered weak (Sturmey, 2006; Willner, 2005), and the appropriateness of CBT for this population continues to be debated.

Evidence to suggest the effectiveness of CBT for people with learning disabilities is largely derived from case reports, case series or single group studies (e.g. Dagnan & Chadwick, 1997; Lindsay, Howells & Pitcaithly, 1993; Willner & Goodey, 2006). Lindsay (1999), in a series of 20 case studies, reported the outcome of CBT for people with learning disabilities (15 with anxiety, 5 with depression). The average number of sessions reported was 23 (range of 15-47). Statistically significant reductions in self-reported symptoms of both anxiety and depression were reported, which were maintained at six month follow-up.

The recent development of controlled studies indicating positive outcomes for the use of CBT for people with learning disabilities has strengthened the evidence-base, although most randomised controlled trials conducted have assessed CBT for anger management (Lindsay et al., 2015). Nicoll, Beail and Saxon (2013), in a recent systematic review of 9 studies (6 group and 3 individual based treatment) using CBT for the treatment of anger in people with mild learning disabilities (8 studies) to moderate or severe learning disabilities (1 study) reported large effect sizes in favour of CBT (uncontrolled ES= 0.88, 95% CI= 0.65-1.12,  $N = 168$ ). However, they noted these finding should be interpreted with caution due to small sample sizes and disparity of studies analysed. Willner et al. (2013), randomly allocated 179 individuals with mild to moderate learning disabilities who experienced anger difficulties to a treatment group (group-based CBT) or a control group (treatment as usual group: TAU). Whilst no significant difference in self-reported anger (primary outcome measure) was found between the treatment and control group, improvements in informant- based (staff) ratings of participants' anger symptoms were found for those in the treatment condition.

Two controlled treatment trials have evaluated the effectiveness of group- CBT for depression in people with mild learning disabilities (McCabe, McGillivray & Newton, 2006; McGillivray, McCabe & Kershaw, 2008). Both studies reported significant improvements in depressive symptoms for participants who undertook the CBT group-based treatment group compared to a waiting list control group. However, the study by McCabe et al. (2006) did not report on the type of randomisation, blinding and masking used (Hassiotis et al., 2013) and lacked treatment integrity analysis (Sturmey, 2012).

A feasibility study for a randomised controlled trial of a 16, one-hour session individual manualised CBT (M-CBT) trans-diagnostic programme for people with mild to moderate learning disabilities experiencing depression and anxiety was conducted by Hassiotis et al. (2013). Thirty two participants were randomly allocated to M-CBT or TAU conditions. CBT was delivered by qualified CBT therapists and sessions were audio-recorded and demonstrated high treatment fidelity. No significant differences on measures of anxiety or depression were found between the groups,

although a non-significant improvement was reported for participants displaying depressive symptoms in favour of CBT. Lindsay et al. (2015) reported the results of a preliminary controlled trial of a trans-diagnostic individual CBT programme for emotional disorders, including anxiety and depression. Twelve participants with mild learning disabilities completed a treatment group of 8-14 sessions (average 10.75) of individual CBT. Treatment participants were retrospectively matched to a control (based on age, IQ presenting problem and problem severity), chosen from a waiting list from another service. Compared to the TAU group, significant reductions in self-reported anxiety and depression were found for the treatment group ( $p < 0.01$ ), along with significant reductions in carer-reported depression ( $p < 0.05$ ). Large effect sizes in favour of the CBT group were also found on pre and post measures of global severity index scores ( $E = 2.05$ ). However, as recognised by the authors, selection of control participants was retrospective, and analysis indicated differences between the control and treatment samples.

Methodological limitations involved in research with this population have been well documented, posing questions regarding the quality of existing research (Sturmey, 2012). The variability between studies, including quality, modality of treatment used and severity of problems and learning disabilities as well as lack of reported measures of intellectual functioning present challenges in using study samples within reviews (Vereenoghe & Langdon, 2013). Descriptions of the specific therapeutic components and procedures administered are often poor within research reports (Prout, Chard, Nowak-Drabik & Johnson, 2000), and it is often unclear how much interventions have deviated from the underlying model used (Whitehouse, Tudway, Look & Stenfert-Kroese, 2006). Consequentially, the effective mechanisms of change, including cognitive and behavioural aspects, within CBT for people with learning disabilities remain unclear (Sturmey, 2006). In addition, it is suggested that most of the research claiming effectiveness of CBT may not be informed by a cognitive distortion model, comparable to traditional CBT described by Beck et al. (1979), but instead informed by a cognitive deficit model which focuses more on self-management techniques (Beail, 2003; Willner, 2005). This is thought to further undermine the evidence-base (Taylor, Lindsay & Willner, 2008). Further methodological limitations have included small sample sizes and lack of control groups, limiting generalisability of reported findings (Sams, Collins & Reynolds,



2006). Ethical concerns including capacity to consent to research participation (Cameron & Murphy, 2007) and the ethics of including TAU groups (Oliver et al., 2002) have also been highlighted.

Overall, the evidence-base for the effectiveness of CBT for people with learning disabilities indicates positive effects. However, numerous methodological limitations associated with much of the research restrict the conclusions that can be drawn. In addition, whilst some controlled studies have included participants with 'moderate' learning disabilities, most have reported including participants with 'mild' learning disabilities. Therefore the effectiveness of CBT for people with moderate to severe learning disabilities may be even less certain. Despite these difficulties, an informal consensus that CBT may be effective for people with learning disabilities seems to exist among many learning disability professionals (Jahoda, Dagnan, Stenfert Kroese, Pert & Trower, 2009a; Willner, 2006a).

#### 1.6.2 The suitability of people with learning disabilities for CBT

Whilst it is accepted that CBT can be effective for people with learning disabilities, it is recognised that some individuals may lack cognitive capacities to engage in all aspects of the model. Research has demonstrated a positive correlation between therapeutic gains and verbal IQ (Rose, Loftus, Flint & Carey, 2005; Willner, Jones, Tams & Green, 2002). However, the links between intellectual ability and predicted therapy outcomes are not straightforward (Flynn, 2012). Measures of IQ alone are considered unreliable indicators of treatment responsiveness to CBT (Taylor et al., 2008) and isolated measures of verbal ability are unrepresentative of ability to engage in CBT (Willner, 2006b).

The Antecedent- Belief- Consequence (A-B-C) model (Trower, Casey & Dryden, 1988) has been used to provide a framework for understanding the conceptual knowledge required to engage in CBT. Within the model, it is assumed that beliefs regarding antecedents (events) act as mediating factors and determine consequences (emotions and behaviours). Various structured assessment methods have been developed based on this framework to determine the suitability of people

with learning disabilities for CBT and to identify which, if any, components of the CBT model may be appropriate. Dagnan and Chadwick (1997) designed a scenario-based task to assess a person's understanding of cognitive mediation. Tasks involved asking participants to identify appropriate evaluative beliefs to present events and emotions. Dagnan, Mellor and Jefferson (2009) later developed this task and provided examples of client responses to assist clinicians in determining which components of the CBT model may be appropriate for clients. Dagnan, Chadwick and Proudlove (2000) expanded on the task developed by Dagnan and Chadwick (1997) and described a more complex assessment, providing participants with more than one possible evaluative belief to choose from. They suggested the complexity of this task is more difficult for people with learning disabilities. Similar findings have also been reported in replication of this study, along with additional tasks, to assess understanding of A-B-C links (Joyce, Globe & Moody, 2006; Oathamshaw & Haddock, 2006; Sams et al., 2006). Kirk et al. (2014) described the use of the simpler task developed by Dagnan and Chadwick (1997) within an IAPT service to assess clients' understanding of cognitive mediation.

Research indicates that people with mild learning disabilities are able to discriminate between events, thoughts and emotions, with the ability to make these differentiations linked with IQ score (Sams et al., 2006) and receptive language ability (Dagnan et al., 2000; Oathamshaw & Haddock, 2006; Sams et al., 2006). Dagnan et al. (2009) reported a significant association between language ability and performance on the cognitive mediation task ( $ES = 0.33$ ). However, as Willner (2006b) notes, whilst studies suggest that people with learning disabilities may demonstrate a good understanding of the link between emotions and situations a much smaller proportion appear able to understand and work with mediating cognitions (e.g. Dagnan et al., 2000; Joyce et al., 2006; Oathamshaw & Haddock, 2006).

Whilst measured receptive language ability and structured pre-therapy assessments may provide a useful indicator of a person's suitability for CBT, Taylor et al. (2008) cautions against denying treatments based upon simple assessments of suitability. They highlight how performance in artificial testing situations is not necessarily translatable into procedural knowledge. Research has indicated that people with

learning disabilities may find it easier to make A-B-C links in real-life dialogues, compared to hypothetical cognitive mediation tasks (Hebblethwaite, Jahoda & Dagnan, 2011). Furthermore, Preparatory training in CBT skills has demonstrated significant improvements in emotional recognition skills (McKenzie, Matheson, McKaskie, Hamilton & Murray, 2000), and in linking thoughts and feelings (Bruce, Collins, Langdon, Powlitch & Reynolds, 2010), indicating clients' ability is often a complex picture which may change over time. Willner (2006b) suggests additional client factors including motivation to seek treatment and perceived self-efficacy as well as therapist's skills and attitudes towards adapting therapy should also be assessed.

Overall, research findings suggest that people with learning disabilities are more able to make appropriate A-C links, compared to A-B-C links. However, the research in this area is still developing and is limited to a few studies. It is clear that the assessment of suitability of people with learning disabilities for CBT needs to incorporate the consideration of a multitude of factors.

### 1.6.3 Modifications and adaptations to CBT for people with learning disabilities

The development of CBT for people with learning disabilities has involved adaptations to traditional CBT techniques and elements of Beck's cognitive therapy (Beck et al., 1979). Lindsay (1999) proposed that through the modification and simplification of techniques, the essential aspects of CBT as outlined by Beck et al. (1979) could be maintained. Cognitive and behavioural techniques are considered effective, provided appropriate adaptations are made (Whitehouse et al., 2006). However, as with CBT for the general population, the effective components of CBT for people with learning disabilities remain unclear (Willner, 2005), creating confusion about how therapy should be adapted. Jahoda et al. (2009a) acknowledge that adaptations are often not evidence-based and highlight the role of the therapist in critically examining the effectiveness of therapy modifications to ensure treatment effectiveness.

In modifying therapy, Hurley, Tomasulo and Pfadt (1998) outlined nine ways therapy can be adapted, suggesting attention is paid to clients' cognitive and verbal abilities, their developmental level and dependence needs. In a comparative review, including 10 CBT studies, Whitehouse et al. (2006) reported on the frequency of adaptations suggested by Hurley et al. (1998). They reported variation in the way CBT was adapted for people with learning disabilities across studies, although noted flexibility in method was frequently considered. Haddock and Jones (2006) explored the views of psychological practitioners delivering CBT to people with learning disabilities. They reported participants generally agreed CBT was appropriate, although recognised difficulties surrounding generalisation of skills and comprehension of abstract concepts, but disagreed on a number of other issues, including the inclusion of support staff and the use of homework.

Within the literature, suggested modifications to the delivery of CBT have included the increased use of experiential activities such as role-play (Jahoda et al., 2009a) and visual aids during treatment sessions in order to facilitate the client's understanding (Brown & Marshall, 2006; Haddock & Jones, 2006; Jahoda et al., 2009a). McKenzie, Matheson, McKaskie, Hamilton and Murray (2001) suggest photographs are more effective in aiding emotional recognition compared to line drawings, whilst others suggest using symbols to simplify concepts and materials. However, in some instances symbols have been shown to increase confusion rather than add clarity (Poncelas & Murphy, 2007). Flexibility in approach is also further encouraged (Esbensen & Hartley, 2013).

A more significant adaptation to CBT proposed the incorporation of the client's wider social context (Jahoda et al., 2009a), which has been emphasised by support staff in ensuring the effectiveness of CBT (Stenfert Kroese et al., 2014). Dagnan and Jahoda (2006), highlight how people with learning disabilities often experience high levels of discrimination and stigmatisation, and CBT needs to consider these real-life experiences as well as the barriers people face in accomplishing social acceptance (Jahoda et al., 2009a). Challenging individual's perceptions regarding social interactions, suitable with clients without learning disabilities, may therefore not be appropriate. Dagnan and Jahoda (2006) suggest alternative strategies aimed at

helping the individual to develop coping mechanisms to deal with social situations and building self-esteem may be more suitable.

Behavioural experiments and homework tasks are considered crucial elements of CBT, enabling the client to directly challenge the validity of thoughts and beliefs (Bennett-Levy, 2003). However, people with learning disabilities may lack the independence or confidence to perform tasks outside of the therapy session and so the use of homework requires careful consideration (Beail & Jahoda, 2012). The inclusion of carers within therapy sessions has been suggested to improve treatment outcomes (e.g. Rose et al., 2005), support the development and generalisation of learned skills outside of the session (Lindsay, Jahoda & Willner, 2013) and provide useful information about the client's situation (Beail & Jahoda, 2012).

It is clear there is a lack of evidence for the effectiveness of specific components of CBT for people with learning disabilities. In clinical practice, Rossiter and Holmes (2013) reported on a NHS Trust-wide initiative, offering suggestions for adapting CBT to people with learning disabilities. The development of a manual for CBT for people with learning disabilities (Hassiotis et al., 2013) encourages practitioners to consider a number of suggestions surrounding the adaptation of CBT. However, the distribution and implementation of these are currently unknown.

#### 1.6.3.1 The therapeutic relationship

Research has indicated the therapeutic relationship to be highly influential in determining treatment outcomes (Keijsers Schapp & Hoogduin, 2000; Lambert & Barley, 2001), and clients' subjective experience of therapy (Elliot, 1986). Individuals with learning disabilities have identified therapists' warmth and empathy as components of effective therapy (Stenfert Kroese et al., 2013). Practitioners working with people with learning disabilities have also described the therapeutic relationship as central to intervention effectiveness (Jones, 2013). However, research has indicated that the development of a therapeutic relationship may be challenging for people with learning disabilities (Dagnan, Jahoda & Kilbane, 2013), with the development of an empathetic and collaborative relationship difficult to achieve (Dagnan et al., 2009). People with learning disabilities may experience higher levels

of interpersonal distrust, influenced by insecure attachment styles from early caregiving relationships and lack of consistency of supportive relationships (Dagnan et al., 2013). They may lack confidence in their ability to change their affective state (Willner, 2006b) and whilst some research has suggested people with learning disabilities may have a realistic understanding of therapy process (Kilbane & Jahoda, 2011), others have suggested they may have difficulty understanding their expected role within therapy and the unique contribution CBT may offer (Dagnan et al., 2013). As such, therapists' role may become twofold: to facilitate client understanding of the CBT model and appropriate interventions, and to help build confidence and self-efficacy around independent problem-solving (Jahoda et al., 2009a). They may need to spend more time negotiating meaning with the client and providing encouragement to facilitate the client's active involvement in therapy (Jahoda et al., 2009b).

Research examining interactions between the client and therapist offer some encouragement that people with learning disabilities can engage in collaborative therapeutic relationships. Jahoda et al. (2009b) reported on an initiative-response analysis of therapeutic dialogue in thirty individual, adapted CBT sessions with fifteen adults with learning disabilities. Findings indicated an even distribution of power between therapist and client dialogues, as well as active participation of clients in sessions. However, in contrast, other research (Kilbane & Jahoda, 2011) has suggested people with learning disabilities may expect the therapist to take a more directive role within therapy. Research exploring the complexities of the therapeutic process between the therapist and clients with learning disabilities, is considered a neglected area (Jahoda et al., 2009a; Jones, 2013; Pert et al., 2013). Whilst careful consideration to the therapeutic relationship may be required, no guidelines exist for assisting therapists in doing so. In the absence of an established evidence-base, therapists need to critically evaluate the effectiveness of any adaptations made to the therapeutic process and relationship (Beail & Jahoda, 2012).

#### 1.6.4 Therapist confidence in delivering CBT to people with learning disabilities

Confidence has been defined as a self-perception regarding one's ability to achieve a task (Betz et al., 2003). The complexities involved in delivering psychological therapies to people with learning disabilities inevitably raise questions about therapists' confidence and perceived competence in working with this population (Mason, 2007). Leyin (2011) notes how The IAPT Learning Disabilities Positive Practice Guide (DoH, 2009b; DoH, 2013) highlights possible practitioner issues which may present barriers to people with learning disabilities accessing services. These include therapists' lack of confidence about working with people with learning disabilities, concerns about building a therapeutic relationship, working with clients' increased vulnerability, and views regarding the inappropriateness of psychotherapies for this client group. Therapist confidence has been highlighted elsewhere as a potential barrier in providing equal access to mainstream health services for people with learning disabilities (Dagnan et al., 2014; Rose et al., 2007).

More generally, research has indicated therapists' confidence to influence therapy outcomes. In a study of 55 therapists delivering long-term solution-focused or psychodynamic therapy to people with anxiety or mood problems, therapists' lower confidence and enjoyment of therapy was predictive of poorer client outcomes (Heinonen, Lindfors, Laaksonen & Knept, 2012). Clients' perceptions of therapists' professional confidence has also been linked to treatment effectiveness and client satisfaction (McGuff, Gitlin & Enderlin, 1996; Saunders, 1999). In relation to learning disabilities, clinicians (including psychologists and psychiatrists) have been found to appear more concerned with their personal competence levels than with effectiveness of therapy when considering the administration of CBT (Mason, 2007). Rossiter and Holmes (2013) also highlight how feelings of inadequacy and pessimism may prevail among therapists working with people with learning disabilities.

Staff working in IAPT services may have limited experience and knowledge of working with people with learning disabilities (Thwaites, 2013), and Dodd et al. (2011) highlights the need to consider the competencies of IAPT clinicians in this

area. Specific training and supervision are considered necessary for therapists delivering therapy to people with learning disabilities (Royal College of Psychiatrists, 2004). However, there appears a lack specialist supervision and formal training available to professionals in this area (Brown et al., 2011) and abilities in adapting CBT for people with learning disabilities are viewed as an additional, rather than core competency within CBT training (Rossiter & Holmes, 2013). A large proportion of mental health practitioners who work with people with learning disabilities are thought to have had minimal training in adapting therapy for people with lower abilities (Beasley, 2004). They may be unaware of guidance relevant to working with people with learning disabilities, of the importance of using this to inform their practice, and how to make adaptations (Heneage, Morris & Dhanjal, 2010; Mesa & Tsakanikos, 2014; Rose et al., 2007).

Research has indicated a relationship between perceived professional confidence and training, with training and supervision resulting in greater confidence. In a review of twenty-seven studies investigating the impact of training on staff working with people with learning disabilities, Werner and Stawski (2012) concluded that training in mental health and learning disabilities increased staff knowledge, skills and confidence. However, whilst literature indicates effectiveness of training on mental health problems for learning disabilities staff, fewer studies have focused on the impact of training for mainstream mental health practitioners delivering psychotherapies to people with learning disabilities (Dagnan et al., 2014).

Recent literature indicates the effectiveness of training on mainstream staff confidence. Heneage et al. (2010) evaluated the impact of a single training session on adapting CBT for people with learning disabilities to a group of psychological well-being practitioners. Findings indicated a significant increase in therapists' self-reported confidence post training ( $p < 0.05$ ) although it is unclear whether these effects translated into practitioners' clinical practice. The sample size was not reported although the authors reference a small size as a potential limitation, along with absence of a control group. No information was reported on the reliability and validity of scales used to measure confidence and no follow up measures were included. Dagnan et al. (2014), reported on a modularised training programme of up to eight sessions delivered to 60 trained therapists (using a range of modalities) from



mainstream services. Four groups of therapists, grouped according to their role and service context, received between two and eight training modules. Pre and post measures of a standardised confidence measure (The Therapy Confidence Scale-Intellectual disabilities; TCS-ID) indicated a significant increase in therapist confidence for all groups following training, with a significant main effect for time ( $p < 0.001$ ). No follow-up data were reported and it is unclear if effects of increased confidence generalised to treatment outcomes. In addition, the sample size was small for some groups ( $N = 8$  for one group). Between group analyses indicated CBT-trained therapists reported significantly less confidence than those without CBT training, indicating professional confidence may be of particular relevance to CBT practitioners.

In a series of presentations published on the national IAPT website, Dagnan (2013) reported on the confidence of IAPT therapists following a modularised training programme on delivering therapeutic interventions to people with learning disabilities. Thirty two PWP's received four training modules over one day and 36 high intensity therapists received eight training modules over two days. Pre and post TCS-ID data for all therapists indicated increased therapist confidence and significant positive change in attitudes to mainstream treatment for people with learning disabilities. All effects were maintained at three month follow-up. Qualitative analysis of 12 interviews with participants (6 PWP's, 6 high intensity therapists) at three month follow-up reported training to have influenced clinicians' practice. Taylor and Harrison (2013) also reported on training delivered to IAPT staff on working with people with learning disabilities and found staff confidence to have increased post training.

Whilst training may increase staff knowledge and confidence, low numbers of people with learning disabilities accessing mainstream services may prevent practitioners from gaining adequate experience to develop their skills (Bouras & Holt, 2004). As low numbers appear to be accessing IAPT services (Hatton et al., 2013), this may be of particular relevance to IAPT clinicians. In addition, Rose et al. (2007) indicated staff in mainstream services may feel unskilled and intimidated about work with people with learning disabilities. They also reported staff felt that expertise and

confidence could only be gained through actual experience and supportive working environments.

### **1. 7. Rationale and aims of the current study**

The increasing demand for appropriate psychotherapy for people with learning disabilities has produced both theoretical and practical concerns (Vereenoghe & Langdon, 2013). Whilst there appears to be general consensus that CBT is appropriate for people with learning disabilities, the debate regarding effective mechanisms of therapy is on-going. A developing evidence-base has begun to consider the necessary reasonable adjustments needed whilst delivering CBT within IAPT services to people with learning disabilities. However, a shift towards the evaluation IAPT services for this population is now required.

There is a clear ethical and human rights based argument for the provision of accessible and effective CBT for people with learning disabilities. However, despite government initiatives and highly resourced IAPT services, it is not known whether people with learning disabilities are accessing or benefiting from them (Taylor & Knapp, 2013), or how therapists are responding to their needs. Therapists appear to be faced with limited training, guidance and specialist supervision which may influence their competencies and confidence, consequently impacting therapeutic outcomes.

This research aimed to explore high intensity therapists' experience of delivering CBT to individuals with learning disabilities within IAPT services. It aimed to explore therapists' understandings about the current theoretical arguments around needing to modify CBT for people with learning disabilities, their perceived confidence in doing this within the context of IAPT services, as well as some of the potential issues which may make therapeutic aims difficult to achieve. Therapists' confidence was explored through the use of the TCS-ID to help understand the perceived impact confidence may have on therapists' experiences. It was hoped that findings would inform training, as well as highlight the on-going support needs of therapists working with people with learning disabilities in IAPT. This project focused on the

experiences of high intensity therapists rather than psychological well-being practitioners, as it was thought that the more formulation-driven and in-depth therapy provided by these clinicians may provide a richer understanding, and anecdotally people with learning disabilities appear more likely to receive high intensity IAPT services if they access IAPT at all.

### 1.7.1 Research Questions

What are the experiences of a sample of high intensity therapists delivering CBT to people with learning disabilities in IAPT?

- What information are therapists drawing upon to inform their work with people with learning disabilities?
- What are the successes and challenges of delivering CBT to people with learning disabilities within IAPT?
- What training and support do therapists delivering CBT to people with learning disabilities receive and how do therapists perceive this to impact upon their confidence?

## **2. METHODOLOGY**

### **2.1 Epistemological position**

This study adopts a position of critical realism to explore individuals' constructions of their own experiences. Critical realism can be considered to be positioned between realism assumptions, which assume reality can be directly observed, and social constructionist perspectives, where many versions of reality exist (Harper, 2012). Critical realism assumes that the way reality is perceived is partially dependant on one's own beliefs and expectations (Finlay, 2006) and whilst it acknowledges the existence of an independent existing reality, it accepts that direct perceptual contact with this reality cannot be achieved (Willig, 2008). From this position, the influence of the researcher's lenses in both the examination of the external world and the contribution of knowledge is recognised (Parker, 1997). Critical realism acknowledges how meanings are constructed by both the participants and the researcher. Rather than assuming data collected represents a direct and self-evident reflection of reality, it acknowledges data needs to be interpreted using outside knowledge, theories and evidence in order to develop an understanding of the phenomena under study (Willig, 2012).

### **2.2 Rationale for a choice of qualitative method**

Qualitative research methods are concerned with gaining understanding of people's experiences and how they make sense of certain phenomena (Willig, 2008). Little is currently known about therapists' experiences of delivering IAPT services to people with learning disabilities. However, existing literature has suggested that multiple factors may impact on therapists' experiences; including prior relevant experience and training, therapists' confidence, as well as support and resources available to them in their role. Whilst a quantitative method, such as a survey, may have offered findings that were more generalisable, it may not have allowed exploration of the complex relationship between therapists' confidence, knowledge and perceived skills regarding working with people with learning disabilities and applying this within the

context of IAPT. Conducting an in-depth study with a sub-sample of high intensity therapists was considered most appropriate in order to explore the complexities and relationships between these multiple factors, in order to further understanding regarding the experiences of this group. In addition, preliminary information collected during the early stages of the project development suggested that numbers of people with learning disabilities accessing IAPT services are low and that few therapists have seen people from this population within services. It may have therefore been difficult to achieve a sample size big enough to allow for any type of meaningful statistical analysis if a quantitative method was employed.

In deciding upon a qualitative method, thematic analysis was considered to offer the most appropriate method for the research question and epistemological position taken.

### **2.3 Rationale for thematic analysis**

Thematic analysis is a qualitative research method which provides flexibility in allowing the researcher to adopt a range of different epistemological positions (Braun & Clarke, 2006). As a method, it allows the identification of patterns and categories across data relevant to a research question, which can be conceptualised as themes. These patterns of meaning can be identified at either the descriptive or semantic (manifest) level, in which themes are based upon directly observable data, or at the interpretive (latent) level (Boyatzis, 1998). Whilst realist epistemology is associated with more descriptive themes, constructionist positions may be associated with themes more interpretative in nature. Adopting a critical realist position allows the identification of themes both explicit and implicit in content (Joffe, 2012), and therefore a combination of manifest and latent themes were constructed.

Thematic analysis may be guided by an inductive (data-driven) or a deductive (theory-driven) approach, influencing the development of themes. Whilst an inductive approach is considered to facilitate the generation of themes independent to identified theory and knowledge, a deductive approach is characterised by mapping themes onto previously conceived theoretical constructs and ideas (Braun & Clarke,

2006). The exploratory nature of this research suggested an inductive approach may be best suited. However, it is suggested that as the researcher is often already familiar with the topic's literature, it is not possible to avoid the influence of previous theoretical knowledge within the analytical process (Braun & Clarke, 2012). A dual deductive-inductive approach is also considered useful in permitting the generation of new ideas, whilst preventing the repetition of previous research findings (Joffe, 2012). Whilst a data-driven approach guided analysis within this study, it also incorporated pre-conceived knowledge and theory and thus a combined inductive-deductive approach was adopted. From this position, whilst remaining open to new concepts, theory and ideas about CBT for people with learning disabilities, IAPT and therapist confidence have also informed data analysis.

In considering the most appropriate qualitative method for this project, interpretative phenomenological analysis (IPA) was also considered as a potential method. IPA aims to develop an in-depth understanding about individuals' lived experiences and the meanings they attribute to these, relevant to a particular phenomenon (Smith & Osborn, 2008). However, rather than aiming to provide a detailed exploration of lived experiences of therapists, this research was also interested in exploring the complex interactions between therapists' understanding and opinions about delivering CBT to people with learning disabilities, their understanding of people with learning disabilities as a client group, and the context of IAPT in which CBT was being delivered. Thematic analysis was considered appropriate as it enabled exploration of the complex interplay between these factors to consider how they may influence therapists' experiences.

Whilst IPA may have offered a more detailed examination of the lived experiences of high intensity therapist working with people with learning disabilities in IAPT, it is less consistent with a critical realist position. Whilst IPA holds a distinct epistemological position about experiences as distinct from realist or constructionist, thematic analysis allows a critical realist position to be adopted, which was considered most appropriate for this research.

## **2.4 Researcher reflexivity**

In ensuring the quality and transparency of qualitative research, it is important for the researcher to acknowledge and critically reflect upon, the reciprocal and inter-subjective relationship between the participants, data and researcher (Yardley, 2000). Personal reflexivity involves the critical reflection upon how one's own identity (including beliefs, values and experiences) has influenced and shaped the research process, including the analysis (Willig, 2008). During the process of analysis, the researcher is thought to play an active role in the identification and development of themes. The researcher's own interpretation is placed upon the data to create and interpret codes and themes, rather than themes 'emerging' from the data (Braun & Clarke, 2006).

Of relevance to this research is my professional experience and training, having completed a post-graduate diploma in CBT, and working in both IAPT and learning disability services. Whilst this experience may have facilitated my ability to sensitively develop a picture of the experiences of IAPT therapists, I was aware that I also needed to remain open to exploring how this may have led to possible biases influencing the research process (Thompson & Chambers, 2012), and may mean I was more receptive to certain issues. In consideration of the impact this may have had on my ability to remain objective and neutral throughout the research process, I kept a reflective journal from the initial stages of the project to development up until report writing. Selected extracts have been included in Appendix 2, referenced within the body of this report where relevant.

An important stage in my reflexive process was during the recruitment phase of my research. During this phase I contacted a significant number of IAPT services, although experienced difficulties in recruiting services for my project. A number of service managers whom I approached appeared to hold negative attitudes around the appropriateness and relevance of IAPT service for people with learning disabilities. I was mindful that I needed to be aware of how my own reactions to these experiences may influence my own position, particularly at the data collection stage of my research (see Appendix 2.1 for an extract from my reflective journal demonstrating these reflections).

## **2.5 Participants**

### **2.5.1 Recruitment**

Participants were recruited from five IAPT services across three different NHS Trusts within the greater London area. Following discussions with service managers, approval was obtained from the relevant research and development service. Following this approval, potential participants were approached about the research and provided with a participant information sheet (Appendix 3) through a team email (Appendix 4) or by the researcher presenting the research at a team meeting (see Appendix 5 for information covered during presentation). Staff members were invited to contact the researcher if they wished to participate in the research. The research was fully discussed with all interested parties individually, including details of participation and ethical considerations, and those that wished to participate were provided with a participant consent form (Appendix 6) via email. Following receipt of a signed and initialled consent form, the participant was sent the TCS-ID via email, which they were asked to complete and return to the researcher prior to the interview meeting. An interview date was then arranged.

Inclusion criteria for this study included therapists who were currently delivering high intensity therapies within an IAPT service and had experience of delivering CBT to at least one individual with learning disabilities in an IAPT service.

The terms 'learning disabilities' and 'learning difficulties' can often be confused. The researcher therefore clarified participants' understanding of learning disabilities and the nature of their clients' impairments. A definition of learning disabilities was also provided in the participant information sheet (Appendix 3).

### **2.5.2 Sample**

Ten high intensity therapists volunteered to take part in a single semi-structured interview and the completion of the TCS-ID. It was not possible to determine the number of potential participants across services, although information gathered



during the recruitment phase suggested very few high intensity therapists had delivered CBT to people with learning disabilities in IAPT.

Participants held a range of professional qualifications, including professional doctoral level clinical or counselling psychology qualifications and high intensity diplomas. The sample included a total of seven qualified clinical psychologists, one trainee and one qualified counselling psychologist, and one high intensity therapist who had diploma level training. Five of the participants had completed a high intensity IAPT diploma. One male therapist and nine female therapists participated within the research, and of these two also held part-time managerial roles. Some participants reported having only delivered CBT to one client with learning disabilities in IAPT, whereas others reported having worked with “a few”.

To protect participant anonymity it is not possible to provide a breakdown of participant demographics including gender or professional position. Pseudonyms have been carefully chosen to protect anonymity, with a number of gender- neutral names used.

Data saturation within qualitative methods is thought to occur at the point when, despite interviewing more participants, further data do not lead to new information regarding the research questions and developed themes (Guest, Bunce & Johnson, 2006). It is estimated that data saturation is achieved at approximately 12 interviews, although basic elements for main themes may occur at six interviews (Guest et al., 2006). This study therefore aimed to recruit as many participants as possible within the permitted time frame of this project, with a minimum of six.

## **2.6 Data collection**

### **2.6.1 Therapy Confidence Scale-Intellectual Disabilities (TCS-ID) administration**

Prior to the interview, participants were sent the TCS-ID via email, which they were asked to complete and return to the researcher. If they were unable to complete this

before the meeting, they were asked to do so at the start of the meeting, prior to the interview commencing. All participants completed the measure.

### 2.6.2 Interview process

All interviews were held at the participants' place of employment, although participants were offered a choice of meeting locations (in which privacy and confidentiality could be maintained). Interviews ranged between 50- 75 minutes in length.

All interviews commenced with a conversation about the type of questions participants may be asked and the participant information sheet and consent form were discussed again. Emphasis was placed upon the participants' choice to refrain from talking about anything they did not wish to, as well as their right to terminate the meeting at any point. Confidentiality was also fully discussed prior to the interview commencing. The number of questions and the order in which they were asked varied between interviews, and were guided by the process of free speech in conversation. This attempted to minimise the researcher's impact upon the interview process. Participants were asked about their experiences of delivering CBT to people with learning disabilities within any IAPT services. A number of participants had previously worked in other IAPT services, and chose to also report on their experiences in these services where relevant. Interviews ended with an opportunity for the participant to reflect upon the interview process and to debrief. All potential risk issues regarding clients were fully discussed with participants, although no current risk issues were identified.

### 2.6.3 Measures

#### 2.6.3.1 The Therapy Confidence Scale-Intellectual Disabilities (TCS-ID)

The Therapy Confidence-Scale – Intellectual Disabilities (TCS-ID) (Dagnan et al., 2014) has been developed to measure the confidence of therapists in delivering therapy to people with learning disabilities. Participants answer 14 items related to

various stages of the therapy process, including assessment, intervention, and therapy ending stages, on a 5 point Likert scale (ranging from “not confident” to “highly confident”). The TCS-ID items are generic to any therapeutic modality, although the scale has been used with CBT therapists (Dagnan et al., 2014; Thwaites, 2013). The authors reported good psychometric properties (Cronbach’s  $\alpha = 0.93$  and test-retest reliability = 0.83). They also suggested its ability to discriminate between groups of therapists with prior relevant training of working with people with learning disabilities, compared to those without, indicates a degree of validity for the scale.

The scale is described as measuring a single construct of confidence, although Dagnan et al. (2014) noted how therapists appeared to be identifying different levels of confidence for skills they perceived as generic, including listening, empathy and forming a therapeutic relationship (where higher levels of confidence were reported), compared to those they perceived to require more specialist knowledge, including using specialist assessments and explaining results of assessment (which received lower ratings).

The questionnaire was used to situate the population sample regarding confidence levels. It also informed discussions during interviews, including whether participants perceived their confidence to impact upon their experiences. Quantitative data from the TCS-ID were not used for analysis.

#### 2.6.4 Materials

##### 2.6.4.1 Digital recorder

All participant interviews were recorded using a digital voice recorder (Olympus VN-5500PC). Participants were informed that interviews would be recorded, both prior to the arrangement of interviews and again directly before the interview took place.

#### 2.6.4.2 Interview schedule

An interview schedule (Appendix 7) was developed following the completion of a comprehensive literature review and following discussions with my supervisors, two clinical psychologists experienced within the research area. The interview schedule was used to guide questioning within interviews. Rather than being used in a prescriptive way, it mapped out areas of possible questioning and interviews remained participant led to encourage therapists to discuss issues that were relevant to them. The interview schedule was developed prior to the recruitment process.

A pilot interview is considered useful in determining the appropriateness of the interview design and research questions (Turner, 2010). A pilot interview was conducted as a consultation exercise to check that the interview schedule was appropriate for the target audience. It was not used for data collection; therefore ethical approval was not considered necessary. However, ethical implications of this exercise were carefully considered, including within supervision. All procedures used for research participants from whom data were collected from were followed for the pilot interview. This included ensuring the participant was fully aware of the purpose of the exercise, ensuring participant anonymity, and that they were aware of confidentiality. As with all research participants, the pilot interviewee was provided with the opportunity to debrief and the interviewer was aware of supporting agencies in case of potential distress, although this did not arise.

The pilot interview was conducted with an individual who had prior experience of working with people with learning disabilities in an IAPT context and who could therefore comment on the appropriateness of the interview schedule. The participant was a previous professional colleague of the researcher. The pilot interview was conducted following UEL and NHS research and development approval and prior to interviews being conducted with research participants from which data were collected.

The pilot interview was transcribed and this was used for the researcher's development purposes. The researcher's supervisor provided feedback to the researcher regarding their interviewing style. All data were destroyed following this feedback. Following this process, it was decided that the interview schedule was

appropriate. A reflective journal extract following this process may be referenced in Appendix 2.2.

## **2.7 Ethical considerations**

### 2.7.1 Ethical approval

The University of East London Research Ethics Committee provided ethical approval for this study (Appendix 8). Amendments to the original ethical approval application were required and approved (see Appendix 9 for email documentation confirming approval of amendments). Research and development approval was also obtained from the three NHS trusts that participants were recruited from (see Appendix 10 for copy of approval letters)

### 2.7.2 Consent and anonymity

Participants were informed that all information collected, including names and other identifying information, would be kept confidential. They were informed that anonymised extracts from interviews would be viewed by the research team and examiners, and would be included within the final write-up of the research. Participants were allocated an identifying number, later changed to a pseudonym for the purpose of the report, and only the researcher was aware of individual identities.

All identifying information, including consent forms were kept securely and separately from voice recordings, transcripts, including extracts and TCS-IDs. Participants were informed that following the examination and award of the doctoral research, audio-recordings would be destroyed, and that anonymised transcripts would be held securely for five years post submission, in accordance with good practice in research guidelines outlined by the University of East London.

## 2.8 Data Analysis

### 2.8.1 Transcription

Audio-recordings of all interviews were transcribed verbatim by the author. Thematic analysis does not require the same level of detail within transcripts as other types of qualitative analysis, although should include a verbatim account of relevant verbal and non-verbal (where appropriate) utterances (Braun & Clarke, 2006). The transcription conventions used to transcribe data were based upon the transcription scheme outlined by Parker (2005) see Appendix 11 for convention key used. All identifying information was removed and transcriptions were checked for accuracy through listening to each interview again, whilst reading the relevant transcript. During this process hand-written notes were made regarding initial areas of interest to start the process of analysis of meaning (Braun & Clarke, 2006).

### 2.8.2 The process of thematic analysis

This analysis followed the stages of thematic analysis outlined by Braun and Clarke (2006) in a recursive process, as outlined below.

#### *Phase one: Familiarisation with research data*

Following accuracy checking of interview transcripts, these were read repeatedly to enable further data familiarisation. Hand-written annotations regarding areas of initial interest were made in the left-hand margin.

#### *Phase two: Generation of initial codes*

Each transcript was re-read and analysed individually. Potential codes were annotated on transcripts (right-hand margin) to attempt to capture what was being said by the participant. Each transcript was coded systematically in its entirety before moving to the next set (see Appendix 12 for an extract from one of the transcripts demonstrating both annotated comments and codes). This research was concerned with the experiences of high intensity therapists delivering CBT to people with learning disabilities and therefore this remained the focus of analysis. Information

about the guidance and support therapists received, as well as organisational issues relevant to these experiences was also represented in the analysis in order to provide insight into therapists' experiences. Extracts, including surrounding details to retain context (Boyatzis, 1998), were collated for each code in a separate word document, and occasionally extracts were copied into more than one code. Exceptions and inconsistencies in the data were also coded. Codes were clustered into groups to facilitate the identification of potential relationships and themes. A detailed account of the analytical process is included in Appendix 13, including a list of identified codes (Appendix 13.1) and examples of coded extracts (Appendix 13.2).

#### *Phase three: Searching for themes*

Potential themes were generated from the grouped codes. All data extracts for individual codes were collated into the relevant theme. Again, themes were clustered to help identify higher-order themes. The relationships between codes, sub-themes and higher-order themes were considered and codes and sub-themes were further combined to create potential higher-order themes. Fifteen higher-order themes were created, which are illustrated in Appendix 13.3.

#### *Phase four Reviewing themes*

Level one: This phase involved checking the consistency of themes against data extracts, to ensure each theme was supported by relevant coherent data. Themes that were not distinctive enough or themes that only received little mention were collapsed into broader themes, split or re-worked. A characteristic of thematic analysis is its recursive process, and therefore the analysis was altered and modified as new ideas developed. A "thematic map" (Braun & Clarke, 2006, p.21) was created following the collapsing of fifteen potential themes into six higher order themes, as illustrated in Appendix 13.4.

Level two: This phase aimed to check the reliability of the themes through re-reading the entire data set. This process enabled the identification and inclusion of missing data from exiting themes, and enabled the original thematic map to be re-structured appropriately. The final themes and sub-themes which were felt to best represent the data can be seen in Thematic Map 2 (Appendix 13.5). When refinements were no

longer considered appropriate, the process of reviewing the data against themes stopped.

*Phase five: Defining and naming themes*

Each theme was reviewed to consider the information it conveyed, and how it linked with other themes to create a coherent story. Further refinement of themes was undertaken to clearly illustrate the information each theme conveyed.



### 3. RESULTS

#### 3.1 Therapy Confidence Scale-Intellectual Disabilities (TCS-ID) scores for participants

A total score calculated from the 14 questions on the TCS-ID indicated participants' perceived confidence. Table 1 illustrates participants' training, level of experience related to working with people with learning disabilities (LD) and total confidence score.

**Table 1**

*Participant TCS-ID scores and professional experience*

ID	Training	Experience of LD work prior to IAPT role	TCS-ID score
Vicky	HI	None	9
Kelly	CP	Limited	23
Alex	HI	Limited	23
Cameron	CP	Limited	25
Jessie	CP	Prior LD placement	31
Rory	CP	Limited	30
Emma	CP, HI	Prior LD placement	37
Riley	CP	Prior LD placement	40
Pat	CP, HI	Extensive	40
Charlie	CP, HI	Extensive	43

*HI: High intensity training*

*CP: Completed clinical or counselling psychology doctoral training*

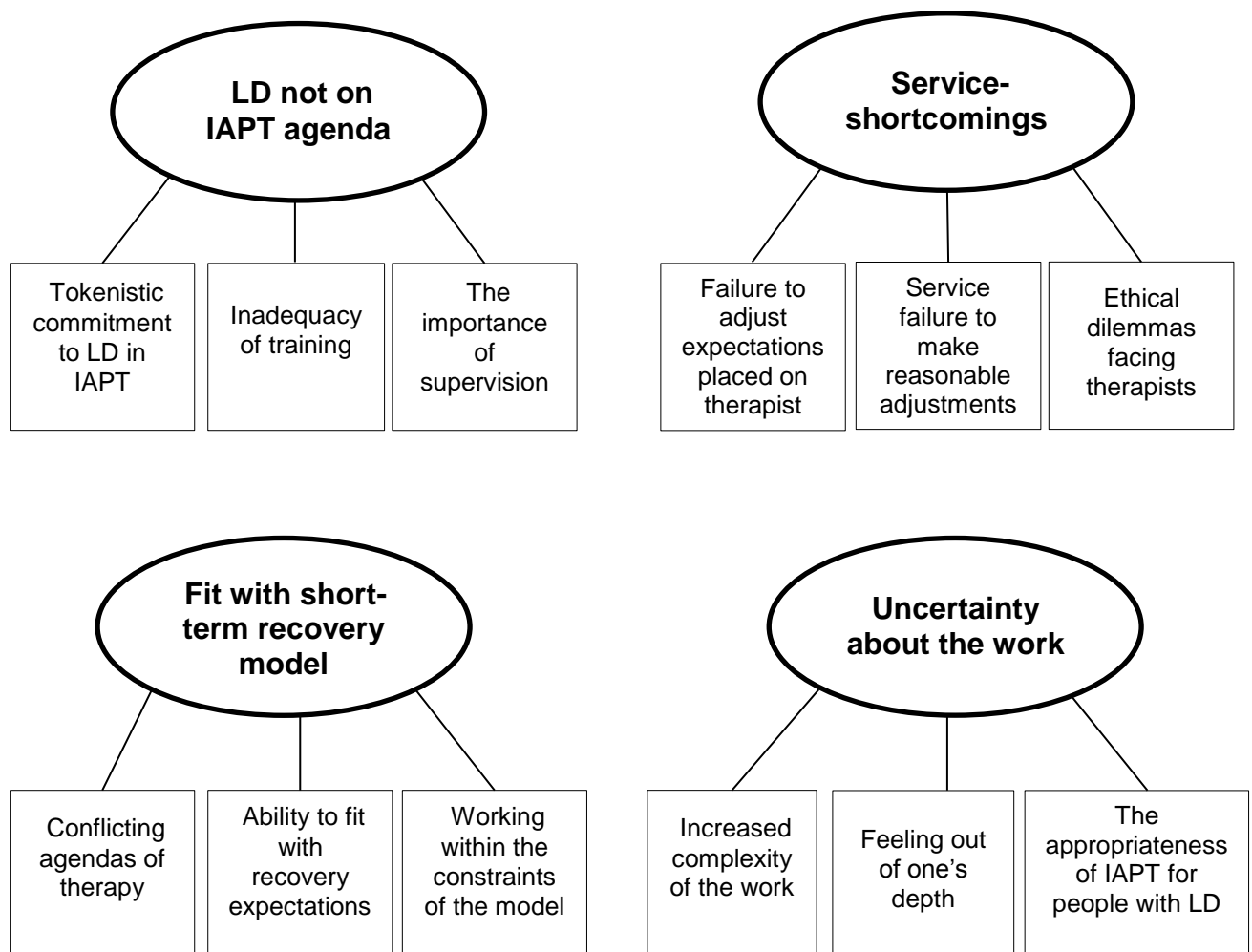
*(Scale range of possible TCS-ID scores 0- 70)*

Quantitative data from completed TCS-ID questionnaires was not used for statistical analysis. Participants' reported confidence will be discussed throughout the results section where relevant. However, it is interesting to note that participants who have scored higher on the questionnaire are those with the most experience of working with people with learning disabilities.

### 3.2 Themes

Four higher-order themes were identified during the analysis process. An overview of the themes and their constituent sub-themes is provided in Figure 1. Each theme is then discussed, and raw data extracts are provided to illustrate these.

An identifying pseudonym and location in the relevant transcript is provided for each extract. Whilst brief interjections and single repetitions were initially transcribed they were not analysed in detail and have been omitted from presented data extracts to improve readability. Words omitted from quotes to reduce length are indicated by "...". Text has been added in square brackets [text] to assist the reader with clarification.



**Figure 1** Thematic Map of themes relating to therapists' experiences of delivering CBT to people with learning disabilities (LD)

### 3.2.1 Theme one: LD not on IAPT agenda

The analysis process revealed an overarching theme throughout interviews relating to participants' experience of learning disabilities being a low priority in IAPT services. Subsequently, this appeared to affect the planning and delivery of interventions for people with learning disabilities within services, as well as the mechanisms of support, training and resources available to therapists. Many described few opportunities to develop their knowledge and skills relevant to adapting CBT for people with learning disabilities, who often seemed a "hidden group" (Jessie: 646) within services.

#### 3.2.1.1 Sub-theme: Tokenistic commitment to LD in IAPT

During the course of interviews, a number of participants felt that whilst IAPT services were available to people with learning disabilities, this population lacked management focus. Service provision was experienced by some as more of a tokenistic and "tick-box" (Charlie: 325) response to policy guidance. Some participants felt there was insufficient attention to identifying the needs of people with learning disabilities who access IAPT and described a "switching off" (Pat: 344) by management in relation to the complexities involved with the work.

Two participants described their role as the lead person in their service for people with learning disabilities. However, all other participants noted that whilst many areas of specialism (e.g. older adults) were allocated a 'champion' within their service, often no one was identified as lead for 'learning disabilities'. Accordingly this user group often felt hidden, perhaps highlighting the lack of inclusivity of learning disabilities within services.

Most clinicians will have an area in which they will lead or take a special interest and I do feel that learning difficulties is probably an area that's perhaps overlooked a little bit or um it's not so clear err it feels quite hidden ... I'm quite sad really about it and it think that it's something that needs to change and I think um there's you know a proportion of the society that's probably not um not held in mind as much as other areas and it all seems to

depend on kind of streams of funding ... I think learning disabilities are one of those areas that perhaps at the moment for whatever reasons- and probably a number of reasons- it's not it's not as high up that agenda as it should be (Jessie: 619).

Some participants reported how 'learning disabilities' as a topic was rarely spoken about in team meetings, unlike other client groups. It appeared that rather than it being a broader area of interest within IAPT services, it was more dependent upon motivated individuals to raise awareness and develop services for this group.

There was a- somebody in the service who was interested in it and passionate about it and therefore put the time and energy in to it um and I think that really makes a difference when you have somebody in the service who's that's their passion and they wanna do something about it. Then it will become higher up the agenda because they'll talk about it more and they'll push and they'll do things and they'll circulate information and they'll sort of talk to people about it and everyone will get more aware (Riley: 595).

The invisibility of learning disabilities within services was perhaps also reflected in participants' limited awareness of relevant policy and literature. Seven of the 10 participants had not heard of the IAPT Learning Disabilities Positive Practice Guide. Those who were familiar with the document had more experience of working with people with learning disabilities and had expressed a personal interest in the area. They described the guidance document as largely lacking in direction regarding how adjustments should be made, and felt it offered no real application to practice.

I think the "how" tends to be missing and I think this is because I think when you come up with things like guidelines and stuff I think it's important to see how realistic they are and what can be done to make them realistic, so I think a lot of "hows" are missing. (Pat: 835).

That's something again that comes up all the time with thing what is a reasonable adjustment ... we're supposed to offer it- at the high intensity up to 12 sessions, so is the reasonable adjustment 15 sessions is it? But there's no there's no kind of clarity or um around that, there's no clarity (Alex: 811).

The lack of guidance provided by the IAPT Learning Disabilities Positive Practice Guide perhaps further reflected the lack of management focus regarding the provision of services for people with learning disabilities, as highlighted by one participant.

That's what struck me is I thought this is really thin ... I just remember looking at this- this is not much really here not much beyond um how do I say this rhetoric sometimes. I think sometimes you know things sound better and they sound good and politically they sound great, but it's like well okay how do we make this happen meaningfully. There's less- less direction about how ... where was the sit down and thinking versus let's roll it out and then work it out (Charlie: 927).

It seemed that whilst there was some recognition that working with people with learning disabilities could be difficult, it was not an area that was given much attention.

Yeah there isn't, there hasn't been any guidelines there you know even a kind of a A4 kind of description of kind of ideas of how to adapt there's really not been anything like that and in supervision err people always say "whoa it's a bit tricky, isn't it". And people try and do the best they can but there actually isn't any kind of there hasn't been any knowledge there to help (Vicky: 469).

From an organisational perspective, many participants described a lack of clarity about service provision for people with learning disabilities. Many felt better communication with the local learning disability services would be beneficial in

achieving better service pathways, as well as providing a source of knowledge and guidance.

### 3.2.1.2 Sub-theme: Inadequacy of training

A recurrent theme for many participants was the importance of knowledge and training regarding work with people with learning disabilities. Therapists who had previous training or experience described relying heavily upon this to guide their work, and participants who had little training highlighted this as an area of need. Half of the participants had completed a high intensity IAPT training diploma (at various institutes), all of whom reported there had been no mention of working with, or adapting CBT for, people with learning disabilities. Some participants felt the IAPT course did not adequately prepare therapists for the work they are expected to do within their roles. Asked whether their IAPT training included adapting CBT for people with learning disabilities, one participant responded:

Absolutely nothing, and that's what really concerns me if I am honest. I think the training is fantastic in a lot of ways for CBT, however the pace in which IAPT services are expanding I don't know if the training is keeping up with it, and trying to cram it all into one year ... The training course didn't really cover LD per se, it covered a bit on older adults but not necessarily learning disabilities, which was concerning (Charlie: 110).

One participant noted the contradiction of IAPT aiming to increase access to psychological therapies, yet excluding the adaptation of therapy for people with learning disabilities within their training curriculum. Some participants appeared to feel that learning disabilities represented an 'extra' role, rather than a core part of IAPT services.

It's odd that that's not in the curriculum really, given that you want to improve access. I mean the clues in the title isn't it [laughs]. Um yeah it is really odd, but again I didn't think about that when I was on it. I guess cos the mind-set is

very much just kind of adult mental health and rather than thinking outside the box ... now I look back it does seem a bit crazy (Emma: 1230).

Some participants felt IAPT failed to recognise the additional training and support needs of therapists working with people with learning disabilities. Those with more training reflected how inexperienced therapists may not be equipped with the skills necessary to work with people with learning disabilities, without prior training.

You're trying to not lose track of, you're trying to juggle obviously the person that's being referred the family ... so trying to hold all of that in one go I think if you've not had some sort of training around that that's just anxiety provoking I think and it's quite hard for clinicians to be put in that position (Charlie: 228).

Nearly all participants identified a need for more training opportunities regarding work with people with learning disabilities, with some envisaging this as a way of increasing their confidence. Typically, participants felt more guidance was needed relating to how to adapt CBT and felt case examples would be useful to contextualise their learning. However, it seemed that the low numbers of people with learning disabilities accessing IAPT services prevented investment in resources and training.

I think it would be something that we would set up if we had more referrals probably, so we probably have just enough to make clinicians like me like a bit anxious, but not enough that we've identified this need (Kelly: 704).

Some participants recognised this as a double-bind, or “chicken and egg” scenario, as without appropriate training and support, therapists may remain ill-equipped to work with people with learning disabilities, who in turn are not referred to IAPT services which may not be deemed able to meet their needs

Cos we don't really see that many people with a learning disability within IAPT, then obviously you might think there's not much demand for that training ... It's kind of chicken and egg isn't it- you'd want people to be trained before you encourage more referrals um so people were able to modify stuff (Emma: 610).

#### 3.2.1.3 Sub-theme: The importance of supervision

For some, supervision was described in a positive light, typically experienced as supportive and helpful.

I sought a bit more supervision just cos I wasn't I wanted to check out I was doing the right thing and um so that in that sense that really useful (Emma: 838).

However, for others, supervision was experienced in a more negative light, described as unhelpful. In these instances, supervision was described as lacking understanding of the complexities involved with the work, and as such failed to provide therapists with appropriate direction for their work.

I would say that having taken her to a supervision group and really having very thoughtful good colleagues actually it didn't translate into kind of help on the ground with this client. I got a really thoughtful, um I got a really thoughtful response to what might be going on for this client, but I didn't necessarily -um that didn't necessarily give me more skills to work with her specific difficulties (Kelly: 587).

To be honest the supervision is poor for learning disabilities. There isn't anyone here that's specialist in it and um the advice that I'm usually given is just do behavioural work and that that's kind of it (Vicky: 60).



Some participants linked supervision to increasing confidence regarding the work and felt they would benefit from more specialist support.

As lovely as my supervisor is, she's not specialised in LD ... what can sometimes help is when you're able to really have someone ... who has a lot of experience and then that can help with the confidence as well because then you feel like you can kind of it helps with the developing of the skills more ... I think that can be some- that can be difficult in an IAPT service because it's not a specialised service for learning disabilities (Pat: 973).

Two participants described seeking support from the local learning disabilities team. One person described how their clinical supervision was provided by a psychologist from the local learning disability team, who was described as an "advocate" for increasing accessibility to people with learning disabilities.

I have fortnightly um supervision with one of the clinical psychologists in the LD service, which is really helpful um, I also, I mean to be honest I basically have her on speed dial (Alex: 503).

Three participants reported attending 'action learning sets' run by the Foundation for Learning Disabilities which they described as providing useful guidance around adapting materials in IAPT services, including the minimum data set (MDS) for people with learning disabilities.

### 3.2.2 Theme two: Fit with short-term recovery model

Another prominent theme throughout interviews related to participants' experiences and perceptions regarding the short-term recovery model underpinning IAPT services, which seemed to lack the necessary flexibility for people with learning disabilities. The service driven targets guiding therapists' work appeared to sometimes conflict with clients' goals for therapy. Participants described making

many adaptations to therapy whilst working with people with learning disabilities. Whilst many were successful, some participants described the boundaries imposed by the service as making some adaptations difficult.

### 3.2.2.1 Sub-theme: Conflicting agendas of therapy

Some participants experienced the change-focused nature of therapy to conflict with clients' goals for therapy who seemed to value therapy as providing a unique space to be listened to, rather than to achieve change. They described therapy to often feel more like counselling rather than CBT and were conscious of their requirement to move people through to recovery.

It felt a little bit like um it was more a counselling space in some way or a space a safe space for her to talk out about things rather than perhaps the traditional kind of model of working ... action based work like work between sessions ... it felt that maybe what she wanted or needed more was sort of a space to talk but I was aware of perhaps getting a bit of a clear remit as to you know what we had to work with, because I suppose hanging over me that that you know our service is only a kind of brief relatively brief sort of number of sessions (Jessie: 138).

Some participants felt uncomfortable about imposing a change model on to clients, and were concerned how the client may experience this.

I have a worry that it's quite perplexing for her that she's coming in to tell me how she feels bad and I'm telling her to go and meet her friend or her sister for coffee ... I'm not sure she wants to make behavioural changes I think she wants someone to listen ... so that's a bit of a conflict as well (Kelly: 868).

A kind of sense of it feeling a bit unfair for the for the patient... in that that they were coming for help and the type of help that was being provided perhaps didn't fit with their needs appropriately (Vicky: 298).

Another strong narrative that appeared to relate to conflicting expectations of treatment was participants' difficulties surrounding the ending of therapy, described by many as "tricky" to manage. This seemed consistent with some participants' responses on the TCS-ID suggesting lower confidence regarding therapy endings. Some observed how lonely their clients with learning disabilities appeared to be and felt they seemed to "latch on" to the support provided by therapy, and that clients seemed reluctant to end therapy for this reason.

It was very tricky ending actually, um there was a sense of her coming to therapy because she felt quite isolated and that when the therapy was ending that- yeah that she would be kind of going back and feeling that again (Vicky: 855).

#### 3.2.2.2 Sub-theme: Ability to fit with recovery expectations

Participants' narratives indicated how services seem to be geared up to moving people through recovery, with clients expected to demonstrate improvements in functioning, as determined by the MDS.

In IAPT there's a big pressure on everyone making recovery in a certain amount of time so the scores going from a certain number to another number (Alex: 305).

One participant indicated how there is often an implicit assessment of a person's likelihood of recovery which affects their access to services.

I don't know if I should say it, but I'm going to say it anyway, um that quite often there's a big focus on recovery rates so when you're assessing if someone's suitable you're also looking at is IAPT actually going to help their scores get down and help so sometimes that can affect people's decision (Emma: 181).

Another participant spoke about how service users with learning disabilities often don't meet the recovery expectations set by the service.

When I will go and have my progress and development review, um you know and if it is the case that not enough people have hit recovery, and it is the case with learning disabilities we will have a conversation about it ... My managers and senior managers and so on they're going to be thinking about what the commissioners are going to think because they're not going to get all these ... explanations to why some people haven't met recovery they're just going to get trends of data and statistics and recovery percentages so it's a really difficult tension (Alex: 364).

Some participants questioned the fit of IAPT's recovery expectations and requirement for service users to demonstrate improvements for people with learning disabilities.

IAPT's commissioned as a err people kind of getting better type of service ... they have to show kind of clinical change and the quality of ... what we're providing and this is based around this questionnaire [MDS] ... so is it yeah is that type of client group appropriate for IAPT services? (Vicky: 690).

### 3.2.2.3 Sub-theme: Working within the constraints of the model

Participants spoke of the need to modify the structure, content and pace of therapy whilst working with people with learning disabilities and described needing to think carefully about how to adapt therapy appropriately.

You can't just go in going alright I'm going to do my social phobia protocol, off I go (Riley: 621).

Nearly all participants reported needing to simplify the content of sessions, often through using more concrete language, as service users with learning disabilities appeared to struggle with more abstract concepts and generalisation of skills. Visual adaptations, including using more pictorial worksheets and drawing, were a commonly reported adaptation perceived to be a helpful way of working with clients. Behavioural interventions were frequently described as being successful and more effective than cognitive interventions, and therefore employed more frequently.

I ended up having to just take a much more behavioural and experimental approach, so trying things in the session so that he could experience them rather than trying to explain them to him (Rory: 169).

Most participants experienced therapy with someone with learning disabilities as more directive and less collaborative than with other service users. For some, sharing a formulation was seen as crucial to collaboration but was not possible, although for others sharing an aspect of the formulation was possible and appeared to be a useful intervention. The pace of therapy was also a frequently described adaptation. Some participants described therapy to involve significant repetition, often due to memory and retention difficulties. Developing rapport also felt slower for some, which was seen by one participant as problematic in a short-term therapy service. Many participants experienced therapy as slower compared to work with other service users.

It was very clear that it was going to take a lot longer than any other assessment, in fact probably than any assessment that I'd done before um and so within, within five minutes I'd realised that I would have to have a second appointment... cos it was all quite slow (Rory: 109).

I think that if she started seeing me without knowing me I think it would have been a lot more difficult to do work with her because here even though they're flexible about doing longer term work it's still short-term work and um I suppose um the difficulty that she has is to open up and to actually talk about issues and you can see how that can be a difficulty in an IAPT service

because of the difficulty of opening up um because the sessions are kind of shorter (Pat: 83).

Participant narratives revealed a strong sense that attending to contextual and systemic factors seemed more necessary, with some viewing it to be crucial to work with individuals with learning disabilities. Many described numerous benefits of involving carers within the work, including supporting the utilisation of therapy skills and therapy endings. However, some experienced carer involvement to be tricky and difficult to manage at times, and felt their involvement required careful management.

For the first couple it just didn't work at all it was terrible ... just pretty much the aunty was just talking ...you could just see the client's frustration ... it was quite tricky ... explaining that normally this type of therapy it is one to one and whilst it's good to have her there for support um it is also good just to have space and just us ... very nicely pushed her away (Emma: 501).

Despite the recognised benefits of carer involvement within therapy, half of participants often experienced difficulties in facilitating their involvement within the boundaries of IAPT. Asked if it was necessary to attend to some of the contextual issues relevant to clients with learning disabilities within therapy, one participant observed:

I think it would have been strange not to include it, but then within IAPT you're getting into a different area. Because IAPT's very much just one to one therapy with them here you don't really do much kind of liaising with other services or like family involvement ... it's a bit of a tricky tightrope but um we did touch on those issues and it was lucky the aunty was there ... you could quite easily stray outside of the remit of IAPT I guess (Emma: 537).

Some participants described needing to cover basic emotions with clients, and that differentiating between, and linking thoughts, feelings and behaviours sometimes

took longer for clients to learn, although could be effective. This may present a difficulty in a time limited service. Some participants described having limited or no success with some aspects of therapy, despite making adaptations.

I learned over the past year actually there's certain things that don't work so well um it's been a bit of kind of a sort of a learning on the job to be honest so I've learned quite quickly things like guided discovery, Socratic questioning don't really work (Alex: 585).

In contrast, some participants reported examples of successful work with their clients. These successes appeared to be dependent upon the therapist's ability to make appropriate adaptations to the work and their client's high functioning, as well as using mostly behavioural interventions.

I think that's what I learned that just doing behavioural work did actually shift something (Rory: 649).

In contrast, one participant felt that no aspects of CBT had been successful whatsoever.

The kind of CBT approach hasn't really worked and that might be how I'm doing it or it might be just because the CBT approach isn't a good option (Vicky: 325).

### 3.2.3 Theme three: Service short-comings

From an organisational perspective, some participants spoke about the extent to which they experienced targets relating to the recovery of clients as unrealistic and at times as "scary" (Alex: 339). Participants felt the time available to respond to the needs of more complex clients is often inadequate, and consequently some therapists experienced the work as more stressful and less enjoyable.

### 3.2.3.1 Sub-theme: Failure to adjust expectations placed on therapist

A prominent sub-theme within this category related to many participants feeling pressurised to meet monthly contact and recovery targets. Some participants felt there was often a fundamental lack of understanding by management of the complexities and time demands of the work, which often provoked therapists' frustration. Targets were often not adjusted to accommodate work with people with learning disabilities, and some participants described having to 'fight' for more realistic expectations.

So you have to see 20 people basically, so they're all very supportive that's great- but you don't kind of get an adjustment in terms of your time ... I fought to get one contact adjustment, so for my, you know, I could be seeing five people with learning disabilities and I have one contact adjustment so I've been dropped down- thinking about whole time equivalent it'd be dropped down to 19 instead of 20. So it's not it's not a lot in the grand scheme of things, in terms of how much extra time it can take (Alex: 509).

Many participants described how additional work "outside of the therapy room" was necessary whilst working with people with learning disabilities, including more preparation of session materials, liaising with the client's system and attending to risk. However, this work was often not recognised.

I certainly felt that doing that extra work wasn't recognised which I found frustrating so you think you're always expected to see the same number of people have the same outcomes (Charlie: 286).

Some participants felt having time to prepare for sessions was important in increasing their confidence about the work. However, the time-pressured and agenda driven nature of IAPT often meant therapists struggled to get the work completed within the time and space provided by management. Searching for



guidance, such as relevant policy documentation was also hampered by having little or no time. This appeared to leave some participants feeling ill-prepared and unconfident about their work, feeling as though they were not able to provide the most effective interventions.

The areas I don't feel so confident ... because I don't have enough time to process ... by not having the time to process and reflect or the time to kind of think about how I'm going to work with the client in a creative way what do I need to do ... that obviously affects the confidence in working with somebody with learning disabilities because I feel am I doing good enough? Because there isn't enough time to get all the other bits done ... to reflect and stuff ... it impacts on my confidence (Pat: 949).

If I had a bit more time, then maybe I could have done a better job ... in sort of choosing how I could have done things in a better way to do with preparation, because there needs to be preparation and I think that is sometimes quite difficult in an IAPT service (Pat: 329).

Some participants reported relying on clients not attending therapy sessions to give them more time to complete their work. Some also described having to forfeit their personal time in order to meet the demands and pressures of the work.

In IAPT there just really isn't time built into your schedule to do anything other than um admin ... any kind of extra reading you'd be doing in your own time (Cameron: 685).

Over half of participants described the work as tricky and stressful, with some perceiving clients with learning disabilities as the most stressful "cases" on their caseload.

I felt very much with her there was a kind of as being more kind of probably stress so I feel like my stress was higher (Jessie: 182).

Many participants described a micro-management and surveillance culture in their work, through monthly target meetings. Some appeared to experience a sense of resentment and reluctance relating to work with people with learning disabilities in response. One participant felt this was due to the extra demands and pressures involved with the work:

IAPT workers are already so pushed for time ... having kind of additional safeguarding issues that are more likely to arise ... working with ... parents or carers and ... lots of liaison work ... it's sort of time consuming so that I hadn't even really contemplated but in terms of um the my expectations of it feeling pressured ... you're kind of hauled into a room every three months ... so it's quite scary ... That potentially is part of the reason why people aren't so super keen to work with people with learning disabilities (Alex: 326).

Feeling unsure and unconfident about the work also seemed to affect therapists' perceptions of working with people with learning disabilities.

I just don't have any training and I'm very unsure of what I'm doing and um I feel a bit heart sink-y when um I know I'm going to be working with someone with a mild learning disability (Vicky: 158).

#### 3.2.3.2 Sub-theme: Service failure to make reasonable adjustments

Whilst adaptations to therapy were often required it seemed that while some flexibility in the delivery of CBT was permitted, a person's diagnosis of learning disabilities would not constitute grounds for extension to therapy.

You could have some flexibility to offer a bit more, but no more than someone with more complicated problems anyway- so just cos they had a learning disability I don't think that would mean you'd go over 18 [sessions], you would still be within that remit of IAPT (Emma: 247).

Some participants' narratives indicated that their attempts to make adaptations for clients were often hampered by practical barriers, undermining their aims of making therapy more accessible. One participant described frustration with not having access to a colour printer to make written work more accessible. Other participants spoke about limited room availability in that whilst adapting the length of the session was possible, in practice it was not easily done. These barriers faced by therapists raise questions about how well IAPT services are responding to equality legislation and requirements to make reasonable adjustments for people with learning disabilities.

I think in theory it's possible ... In practice I think it would be quite tricky um because we only have set clinic times and so you'd have to make sure that they were in a certain appointment where you had a bit of leeway like either at the beginning or at the end and um you know you are booking in people back to back so err in practice I'm not quite sure how that would work (Cameron: 350).

In theory yes, but in reality probably not so with these rooms. For example, you can book yourself into for like an hour and that's it so and then someone else will be booked in potentially the next hour so you could but it would be really tricky (Alex: 850).

Some participants described using some adapted materials available within their service, although others described having none and felt more guidance on how to make adaptations was required. One participant felt they could have made more adaptations than they did. Time restrictions appeared to prevent therapists from thinking and reflecting about their work, including how to make necessary reasonable adjustments for people with learning disabilities.

I didn't have really much time to prepare beforehand so I didn't um particularly take any adapted materials or pictures or anything like that. I just kind of hoped that he would be able to communicate (Cameron: 518).

Some participants considered the standardisation of IAPT, particularly its universal administration of the MDS to be inappropriate for people with learning disabilities. One participant felt the use of the MDS illustrated the lack of consideration paid to the complexities involved with the work.

If you're going to introduce learning disability, older adults all these specialisms, health, you need to have certain measures that are tailored to the different groups. If you're saying they've got different needs then they've got- then you can't outcome in the same way...and I think why wasn't that thought of it before we rolled this out (Charlie: 563).

Another dilemma described by some therapists involved being limited by the number of sessions they could offer to clients, and thus were unable to accommodate the extra work and slower pace of therapy necessary for people with learning disabilities.

If there weren't the constraints of the service then I would have liked to have seen him for longer... I think not being able to continue to see me for longer ... limited what we could get through definitely (Rory: 277).

Whilst some participants reported good attendance of therapy by their clients, some experienced difficulties often resulting from confusion or forgotten appointments. It seemed that whilst trying to be flexible around appointments and non-attendance, this was experienced as a tension in a busy IAPT service.

We would agree an appointment and then she just wouldn't show up. But then I know because I've spoken to her and ... her mum that she'd forgotten those

appointments ... and that she was really sorry, so trying to be more flexible with that policy but it's kind of difficult (Alex 831).

#### 3.2.3.3 Sub-theme: Ethical dilemmas facing therapists

Participants described many ethical dilemmas in their work with people with learning disabilities arising from organisational contexts. Some described experiencing a restricted sense of autonomy and having to adhere to practices they did not always agree to.

Many participants spoke extensively about the use of the MDS, experiencing both the frequency of administration and in most cases, the measure itself as inappropriate. Whilst two participants reported having some flexibility about the frequency of administration, others were required to complete it at every session. Participants described the MDS as often monopolising valuable therapeutic time. Despite their better judgement, participants spoke about having to adhere to service protocol regarding its administration.

I was reading this paper about how it works better when you do it at the beginning or the middle and the end rather than every single week but they do want us to do it every week ... To me I think it just takes a lot of time away from um doing therapy with the client (Pat: 448).

Many participants questioned the reliability and validity of the measure and experienced its administration as difficult.

It's a nightmare. The person I worked with earlier on ... it was four sessions in then I realised it was the mum filling out the questionnaire. So it completely invalidated the whole thing ... So it was like, it doesn't make sense ... I think it's a really complicated thing ... every time I've had to do with people it's been very difficult ... I normally would give it to them in the waiting room, and I then I discovered this ... other person was filling it out, so I started doing it with them in the room (Charlie: 516).

In managing some of the dilemmas faced, some participants described ignoring service pressures and instead focusing on the needs of the client in order to act ethically. However, they described knowing there would be repercussions to deal with.

I have to just kind of try and put it to one side ... by no means an ideal solution ... but just trying not to think about it especially in the session um when I'm with people ... think I'll cross that bridge when I come to it and then have my PDR [progress and development review]. I'll deal with it then (Alex: 420).

To emphasise the dilemmas often faced, one participant, when asked about the MDS administration, described how they were forced to “violate” service protocol, in order to practice in a person centred way. They reflected how it was necessary to conceal their actions from management to avoid potential repercussions.

I had to be pragmatic and I made a decision, which the client agreed to, which was that we wouldn't every session, we'd do it every other session but I'd report the same scores for two sessions...I had to make a clinical judgement on that, I just felt ethically what could I do because I thought this was taking so much time it wasn't helpful for the client and I also feel in terms of the validity at least we're doing every other session. ... I felt this was ... the only way I could really kind of get around it (Charlie: 528).

#### 3.2.4 Theme four: Uncertainty about the work

A prominent theme throughout many participants' narratives was a sense of uncertainty in their work with people with learning disabilities. This appeared to be influenced by both the perceived inadequacies of training and guidance, in addition to the increased complexities associated with the work. Feeling uncertain appeared

to be further exacerbated where the time available to therapists to seek support, read guidance and make necessary adaptation was limited.

#### 3.2.4.1 Sub-theme: Increased complexity of the work

Many participants appeared to experience their work with people with learning disabilities as more complex and uncertain. Some participants described being able to 'sense' clients' learning disabilities almost immediately although seemed unsure about the extent and nature of their difficulties, whilst many commented how their difficulties were not clear at all. Difficulties in assessing clients' abilities and therapeutic goals emerged as a key issue in trying to work out how to deliver therapy.

I don't know how much she understood of it ... I know one particular client, and she presented differently every single time so I couldn't really get a sense of who she is and what she was able to do, and what she wasn't able to do ... Then it's like trial and error so you kind of try and help them understand the formulation ... I kind of think to myself "my God, what am I doing here, she's not getting this at all- it doesn't matter how much I've simplified it [laughs] she's just not getting it" (Pat: 616).

Acquiescence also made it more difficult for some therapists to get a sense of the client's level of understanding and goals for therapy.

Acquiescence came up loads ... they um had a tendency to agree with me and I had to work really hard to get them to disagree with me (Charlie: 142).

Often, there was a common perception amongst participants that the work involved responding to more risk and vulnerability issues, which some felt were further complicated by the client's learning disabilities.

Because of my lack of experience of working with LD I feel like maybe it might be more difficult for me to kind of understand and formulate that kind of risk and know how to manage that, given that he has got LD (Cameron: 74).

Some participants described feeling they held extra responsibility due to the vulnerability of their clients. One participant highlighted how the type of risk issues they faced were different compared to clients without learning disabilities.

At seven o'clock and she told me yesterday "my dad called me up and said if I didn't give him any money he's going to throw me off ... bridge". I just don't seem to get that kind of thing working with a non-LD population (Alex: 483).

The limited time available to complete work raised ethical questions whether therapists are able to respond appropriately to complex risk issues.

I think there's a lot of potential safeguarding issues that I worry about ... it's very time consuming ... writing emails ... and phone calls and um there's so much work in between but there's only so much time so it's just running on nervous energy sometimes especially when you're really busy. You have to be really, really organised and really any little tiny space you've got ... to use that space to try and do the bits in between (Pat: 1201).

#### 3.2.4.2 Sub-theme: Feeling out of one's depth

It appeared there was often a mismatch between therapists' training and competencies and expectations surrounding their role. Many described feeling confused, and in some cases overwhelmed, about what and how to deliver therapy to individuals with learning disabilities. They spoke about experiencing ambiguity about what therapy for people with learning disabilities should encompass

I'm not quite sure if things that I'm saying, how they're being understood. Um I'm not quite sure what pace the therapy should go at, if I'm too quickly, if I'm



making the ideas too complex, too simple um ... if the kind of goals are realistic or unrealistic. Um I suppose in all sorts of ways ... I feel quite out of my depth (Kelly: 442).

Some participants felt their response on TCS-ID items relating to explaining things to people with learning disabilities reflected their uncertainty regarding the appropriate level at which to pitch materials in sessions.

It was really just a guess [laughs], like I didn't really know whether I was doing the right thing or not ... or whether there was a right thing to do (Rory: 251).

For many, it appeared that most of their work was guided by trial and error, rather than more structured and planned interventions.

It was a real on the spot modification ... as I was going, kind of ad hoc "right, ok I'm going to draw like 'a saying', like the mood", instead of writing depressed (Kelly: 794).

We were kind of just going at using interventions and kind of seeing how they were going (Vicky: 125).

This appeared to contrast with some participants' experience with clients without learning disabilities, with whom they felt more certain about protocols. When work was not clear, or work deviated from the protocol, as it often seemed to whilst working with people with learning disabilities, this appeared to create anxiety for some.

It can be quite you know ... de-settling for the clinician who um you know has certain protocols and ways of working and when someone doesn't really fit within any of those to think how you can best meet their needs (Jessie: 1149).

One participant described how their confidence was negatively affected when they were unable to use their normal therapeutic techniques with clients.

I sort of felt like I'd lost my secret weapon that wins people over pretty quickly if I can really quickly show them in a different way what they've told me (Rory: 421).

Consistent with many participants' responses on the TCS-ID, some participants reflected how they felt more confident with relational aspects of the work compared to the specific content of the work. Referring to their responses on the TCS-ID, one participant said:

I feel like on that questionnaire kind of ones I felt more confident were like empathy and so on and I just imagine that's kind of empathising with someone's emotions I think is less um impacted by their intellectual or adaptive functioning, whereas the specialist knowledge part um that you've mentioned feels more about knowing about functioning, so it feels quite -it felt quite different those bits of the questionnaire (Kelly: 430).

Some participants felt their lack of confidence made the work more difficult and in some cases made them weary:

The less confident I feel the more difficult I might find the session (Cameron 594).

I don't feel very confident um not looking forward to working with the person particularly (Vicky: 320).

Many participants felt that confidence related to working with people with learning disabilities was developed through experience, and those who reported feeling more

confident about their work, including the two participants with the highest TCS-ID scores, linked this to having had previous relevant experience. Training was also perceived by some as a way of increasing confidence in this type of work.

#### 3.2.4.3 Sub-theme: The appropriateness of IAPT for people with LD

Some participants' narratives alluded to a sense of uncertainty amongst IAPT staff regarding the general suitability of IAPT for people with learning disabilities. Some questioned whether IAPT had been the most appropriate service for the clients they had seen. Typically, staff seemed to view IAPT as lacking in necessary specialist knowledge and skills to work with people with learning disabilities, and other services were perceived to be more able to meet their needs.

At our team meeting, I think if someone was to say about working with someone with a learning disability that was diagnosed we'd all say there's better services for this person. Maybe because we don't really know what we're doing with people with a learning disability (Vicky: 646).

One participant suggested that a person's difficulties with intellectual functioning may automatically exclude them from CBT and IAPT.

Well in terms of kind of assessing for suitability for CBT there's a kind of clear criteria ... an intellectual understanding is one of the kind of criteria that um makes a client suitable for CBT (Vicky: 140).

Some participants suggested that therapists felt frustrated about the expanding nature of IAPT. It seemed that learning disabilities was not considered to be part of core services, but instead as something 'extra'.

There is a frustration amongst clinicians and perhaps management ... that we seem to be broadening the remit of things that we do ... It's always like something else and something else and something else, and we don't

necessarily have the skills ... we're not necessarily the best people to do the work. Um and if we are being asked to do it, we certainly need a bit of training and a bit of support and specialist supervision. So I would put working with learning disabilities in that ... camp of all the many extra things that we're now doing in a generic adult out-patient service (Kelly: 723).

In some instances, participants suggested that IAPT services may actually reinforce the difficulties people with learning disabilities face in their everyday lives.

It would be so helpful for her to be seen in a specialist service...I think there's an idea that seeing someone with a learning disability in a non-specialist service is normalising ...but I also feel like the difficulties um that this lady faces almost are reinforced by coming to our service (Kelly: 305).

Despite ambiguity surrounding the appropriateness of IAPT for people with learning disabilities, participants recognised how the lack of alternative services often available to people with learning disabilities meant that sometimes people were accepted into the service as there was nowhere else for them to go.

I almost put her on the waiting list because I didn't know what else to offer (Kelly: 654).

However, one participant highlighted the ethical dilemmas surrounding this situation.

Provisions are so poor for people who are diagnosed with a LD at the moment, and then you argue well ... should we be offering a service that isn't really geared up? ... I think there's so many dilemmas here (Charlie: 599).

## **4. DISCUSSION**

### **4.1 Summary of findings**

The aim of this study was to examine high intensity therapists' experiences of delivering CBT to people with learning disabilities in IAPT. It would appear that therapists often experience the conceptual underpinning and service structure of IAPT as being inflexible and providing a poor fit for individuals with learning disabilities. The analysis indicated that people with learning disabilities are often a hidden population within IAPT, and that consideration of this group features minimally within service design, operational management and staff development contexts within IAPT.

Therapists described making many adaptations to CBT whilst working with people with learning disabilities, some of which were successful and led to positive outcomes. However, many therapists felt uncertain about how to make appropriate modifications and reasonable adjustments for people with learning disabilities, and appeared to have limited knowledge regarding relevant literature related to this service user group. Therapists experienced their work with this population as more complex and stressful, compared to their work with other clients in IAPT. Many felt unconfident about making appropriate adaptations to CBT and described adopting a 'trial and error' approach to delivering CBT to service users with learning disabilities in IAPT.

On a systemic level, the infrastructure does not appear to provide therapists with adequate training, support and guidance regarding their work with people with learning disabilities. The tokenistic commitment towards people with learning disabilities described within the IAPT programme appeared to impact negatively on the training, supervision and resources available to therapists in their role. As such, there seems to be a mismatch between the training and support received by therapists and the expectations regarding their role relating to people with learning disabilities. Many felt improved training opportunities and increased access to specialist supervision was needed to support them with their work.

In addition to the challenges presented by working with these more complex clients, the rigidity of the IAPT model appeared to present further challenges for therapists when attempting to adapt CBT. This, in combination with the lack of training and support available to high intensity therapists appears to result in anxiety and low confidence for therapists.

## **4.2 Theoretical implications**

### 4.2.1 Recent developments within the literature

Following the design and data collection phase of this study, a large-scale study was published exploring the views of service users, carers and professionals regarding IAPT for people with learning disabilities (Chinn, Abraham, Burke & Davis, 2014). The report included analysis of survey data from 452 staff (193 IAPT staff and 230 specialist learning disability staff) and interview data from staff, service users and carers (N=27). Findings reported by Chinn et al. (2014) will be discussed in relation to the current study. Other relevant research published since the initial literature search was conducted will also be discussed.

### 4.2.2 The modification of CBT within IAPT

The modification of CBT for people with learning disabilities has been well documented within the literature and many of the adaptations participants described making mapped closely to those reported previously (e.g. Haddock & Jones, 2006; Whitehouse et al., 2006). Participants recognised that strict adherence to CBT protocols suitable for the mainstream population were not appropriate whilst working with people with learning disabilities. Instead they described needing to be flexible in their approach, consistent with the literature (e.g. Esbensen & Hartley, 2013; Whitehouse et al., 2006). The degree of flexibility therapists reported regarding the delivery of CBT appeared variable. However, more consistent were structural and policy constraints which often restricted therapists in delivering person-centred

therapies and hampered their efforts to make treatment adaptations. Many participants described a restricted sense of autonomy, having to adhere to protocols they were not always in agreement with. It would appear that having a learning disabilities diagnosis was not in itself deemed enough to warrant the making of reasonable adjustments, which is concerning in light of The Equality Act (2010), stipulating special adaptations are indeed required. The rigidity of service protocols in IAPT has previously been highlighted as problematic for people with learning disabilities (Chinn et al., 2014), and these issues seemed to create further challenges for the modification of CBT.

Participants experienced people with learning disabilities as more complex, compared to other clients. Difficulties in determining clients' abilities and goals for therapy appeared to make modifying therapy more difficult, as did the presence of acquiescence bias (Sigelman, Budd, Spanhel & Schoenrock, 1981a; 1981b). No reference was made to using structured assessment methods to evaluate clients' abilities in cognitive mediation (e.g. Dagnan et al., 2009). However, some therapists felt work related to distinguishing between thoughts, feelings and behaviours was required prior to employment of other 'goal focused' cognitive and behavioural strategies. Participants also described therapy to involve large amounts of repetition and reported that a slower pace of therapy was needed to accommodate client's cognitive difficulties. However, despite wanting to extend therapy with clients, most therapists were unable to do so, due to service constraints limiting the number of sessions. Consequently, some therapists described a sense of incompleteness when ending therapy with clients with learning disabilities. Arguably, extending the number of sessions for people with learning disabilities to accommodate the slower pace of therapy could be seen as a reasonable adjustment.

The inaccessibility of IAPT materials for people with learning disabilities has been highlighted (e.g. Salmon et al., 2013) and many participants felt materials needed to be adapted. Visual adaptations to materials were frequently mentioned as being effective, consistent with previous literature (e.g. Haddock & Jones, 2006). However, whilst some therapists reported having access to adapted materials, others reported having none.

Practical barriers, including limited access to printing facilities and little time to consider and make appropriate adaptations appeared to create further challenges for therapists in making reasonable adjustments, similarly reported by Chinn et al. (2014). This in turn appeared to create anxiety and a lack of confidence amongst therapists. In relation to adapting materials, many participants described at length some of the difficulties associated with the administration of the MDS with people with learning disabilities. Many felt it was inappropriate, consistent with previous research (Chinn et al., 2014) and in some cases this was despite using adapted versions of the measure. Difficulties associated with the administration of the IAPT MDS for other groups including older adults (Price, 2011) have been reported in the literature. The IAPT MDS has not been validated for use with people with learning disabilities, and the present findings indicate a mixed picture regarding the perceived suitability of the MDS for measuring clients' therapeutic progress. Low numbers of people with learning disabilities accessing IAPT may generate difficulties in using service data to assess the effectiveness of the MDS for this group. However, it is clear this is an issue that requires further consideration.

Whilst the evidence-base remains inconclusive (Sturmey, 2012), previous research examining the use of CBT for people with learning disabilities has utilised both cognitive and behavioural components of therapy. Interestingly, participants described using mostly behavioural techniques with people with learning disabilities, observing them to be more effective than cognitive strategies. Interventions described may also be more consistent with a cognitive-deficit model rather than a cognitive distortion model. There may be a number of reasons for this observation, including limited therapist training and perceived competencies regarding how to work with cognitive components of CBT with people with learning disabilities, or time constrictions influencing the work that can be done. Alternatively it could suggest behavioural strategies may be more appropriate components of CBT for people with learning disabilities. However, recently McGillivray and Kershaw (2015), in relation to the treatment of depression for people with learning disabilities suggested a combined cognitive-behavioural approach in maximising long-term gains in the treatment of depression. This highlights the need for further research in this area in order to develop increased theoretical understanding regarding effective components of CBT for people with learning disabilities.



The incorporation of the client's social context, including the impact of negative life experiences, in the delivery of CBT has been emphasised (Dagnan & Jahoda, 2006; Jahoda et al., 2009a), and many therapists acknowledged needing to attend to wider contextual issues concerning clients. Related to this, participants also recognised potential benefits of including carers within CBT in IAPT, previously highlighted in the literature (Chinn et al., 2014; Salmon et al., 2013). However, in addition to the interpersonal challenges involved with managing carers within therapy, therapists faced further difficulties in facilitating carer involvement within the boundaries of IAPT. The extra liaison work associated with attending to the client's system also generated additional time pressures for therapists, suggesting that whilst potentially beneficial, these adaptations may be harder to facilitate in the context of IAPT.

Many participants described therapy as more 'directive' with people with learning disabilities, in contrast to the more collaborative stance traditionally associated with CBT. Needing to take more responsibility for aspects of therapy whilst delivering CBT to people with learning disabilities has been highlighted previously by Jahoda et al. (2009b), and Kilbane and Jahoda (2011) reported how people with learning disabilities may expect the therapist to take a more directive role. Related to therapy expectations, ending therapy was highlighted by many therapists to pose particular challenges whilst working with people with learning disabilities. Some therapists reported feeling less confident with ending therapy, reflecting responses on the TCS-ID. Difficulties with ending therapy may well be related to clients' lack of understanding about the time limited nature of therapy, as well their expected role within CBT (Dagnan et al., 2013). Many therapists acknowledged the level of support therapy may provide, and suggested clients' dependency on such support may make the ending of therapy difficult for clients. Consistent with Dagnan et al. (2013), many participants felt the ending of therapy needed careful consideration early on in the therapy process whilst working with people with learning disabilities.

The IAPT model appeared to provide a poor fit with the needs of people with learning disabilities. Participants' experienced discomfort when service driven targets conflicted with clients' goals for therapy, who did not seem to have a goal-focused agenda for therapy. Whilst this may be related to clients' limited understanding of

CBT (Dagnan et al., 2013), it may also be due to the way in which CBT appears to be delivered within IAPT including its strict time limited nature and specific focus on recovery, as defined by the MDS. Nevertheless, therapists' discomfort raises questions regarding the clients' perception of therapy. People with learning disabilities may experience difficulties communicating their needs within mainstream services (Chinn et al., 2014) and this therefore warrants further consideration both in IAPT services and in future research.

The high volume and time-pressured nature of IAPT has been recognised within the literature (e.g. Chinn et al., 2014), and managing the demands of high work-loads and ambitious target expectations appeared central to therapists' experiences. In one case, IAPT was described as a "conveyer belt", depicting its high throughput. These pressures appeared to create additional challenges in meeting the needs of people with learning disabilities. The time and energy consuming nature of delivering psychological therapies to people with learning disabilities has been highlighted (Jones, 2013) and this was apparent in many participants' description of their work. Participants reported multiple factors to consider whilst working with people with learning disabilities, including issues related to social context, increased risk issues and vulnerability and that the work invariably involved more preparatory and liaison tasks. However, performance targets were often not adjusted to accommodate these extra demands and were considered unrealistic, generating feelings of frustration amongst therapists. The emotional impact of working with people with learning disabilities was often described in negative terms, for example, as "scary", "heart-sinky" and a "nightmare" and this work seemed to exacerbate difficulties in managing the already time-pressurised role. Consequently, some therapists felt reluctant to work with people with learning disabilities, who may be seen as a burden by IAPT staff (Chinn et al., 2014). These working conditions may do little to encourage therapists to work with this service user group, who have historically received poor therapy provisions as a result of 'therapeutic disdain' (Bender, 1993). Of further concern is that therapists' lower confidence and enjoyment of therapy have been reported to be predictive of poorer client outcomes (Heinonen et al., 2012) and therefore warrants further consideration by IAPT services.

Fidelity to the CBT evidence-base is considered an important characteristic of the implementation of effective therapy within IAPT (Turpin & Wheeler, 2011), and therefore a more rigid adherence to the evidence-base may be encouraged compared to other contexts. Arguably, the complexity and heterogeneity associated with people with learning disabilities and subsequent flexibility required within the delivery of CBT for this group (e.g. Whitehouse et al., 2006) directly conflicts with this rigidity. This was perhaps reflected by participants' anxiety when work deviated from protocols, or when they were unable to use their 'normal' therapy techniques whilst working with people with learning disabilities. Whilst some therapists indicated successful adaptations and reported positive outcomes, many participants described feeling uncertain about how to modify CBT for people with learning disabilities. Such uncertainty may reflect current theoretical limitations in understanding effective components of CBT for this population. However, the 'trial and error' and 'ad hoc' approach to delivering CBT to people with learning disabilities adopted by therapists may give cause for concern. Whilst it is recognised that the adaptation of therapy for people with learning disabilities may be difficult, modifications should nonetheless be formulation-driven and based on assessment of individual needs and abilities (Esbensen & Hartley, 2013). Yet findings suggest this may not always be the case. Consequentially, those receiving therapy may be experiencing inconsistent, possibly inappropriate interventions which should be of considerable concern for IAPT providers. Of further issue are the ethical dilemmas therapists appeared to be facing in their work with people with learning disabilities, as a result of organisational contexts. One participant's disclosure of violating service protocols in order to practice ethically reflects these challenges.

The potential for these conditions to generate unsafe practice in IAPT has been highlighted (Chinn et al, 2014), and the limited time therapists had to reflect within their role often meant they felt unprepared and anxious regarding their work with people with learning disabilities. Heavy workloads have been linked to mainstream staff feeling unable to meet the needs of people with learning disabilities and to restricting good practice (Bouras & Houlst, 2004; Rose et al., 2007; Thwaites, 2013). One participant described running on 'nervous energy' and responding to complex risk issues in such contexts should give cause for concern. Arguably, ensuring that therapists have the necessary competencies, time and support to appropriately

respond to the needs of people with learning disabilities accessing services may constitute a reasonable adjustment (Gibson, 2009). Instead, therapists appeared to compensate for the problematic context in which they practiced by working extra hours to complete their work, in turn potentially affecting the well-being of therapists.

#### 4.2.3 Policy implementation

The implementation of legislation and policy directives regarding people with learning disabilities is crucial for the delivery of equitable IAPT services. However, the inflexibility of the IAPT context and the subsequent challenges this presented for therapists in meeting the needs of people with learning disabilities raise questions regarding how well IAPT are responding to equality legislation. Participants indicated people with learning disabilities often appeared invisible within services. Rather than a dedicated agenda of achieving full representation with services, a tokenistic commitment to this service user group within IAPT was described which echoes previous findings (Chinn et al., 2014). This appeared to impact negatively on therapists' knowledge and awareness of working with this client group. The limited familiarity regarding key policy documents, including the IAPT Learning Disabilities Positive Practice Guide, amongst therapists confirms previous research reporting that the guide is not well known by IAPT staff (Chinn et al., 2014). This suggests this is a wide-spread issue and warrants concerns regarding policy implementation. Related to this, participants also appeared relatively unaware of service protocols and care pathways relevant to people with learning disabilities and described feeling uncertain regarding the implementation of reasonable adjustments for this service user group. Consistent with previous concerns (Dodd et al., 2011), those who were familiar with the IAPT Learning Disabilities Positive Practice Guide felt it provided little clarity or direction regarding the implementation of reasonable adjustments. Whilst the nature of reasonable adjustments may mean they require individual adaptation, it seems likely services and therapists would benefit from more direction.

Interestingly, participants alluded to learning disabilities being perceived within services as something 'extra', rather than part of core services, which does little to encourage inclusivity for this group, as emphasised by Valuing People (DoH, 2001).

Participants also suggested a sense of frustration amongst IAPT staff regarding the expanding nature of IAPT services. Arguably, this may be related to the lack of representation of people with learning disabilities within services (Hatton et al., 2013) or to the perception of IAPT being designed to deliver therapy to adults within mainstream populations. It may also be related to people with learning disabilities being viewed as an extra 'burden' (Chinn et al., 2014). However, viewing people with learning disabilities as 'extra' or 'separate' contradicts equality legislation such as Valuing People (DOH, 2001), and warrants attention by services. Related to this, Rossiter and Holmes (2013) highlighted how abilities to adapt CBT for people with learning disabilities are often considered an add-on to IAPT training and service development, whereas they should be viewed as a core competency. This may also influence the way in which people with learning disabilities are viewed within IAPT. Its exclusion from the curriculum also serves to contradict the aim of inclusivity within IAPT, as highlighted by one participant.

#### 4.2.4 The training and supervision needs of high intensity therapists

The importance of specific training related to working with people with learning disabilities in IAPT was emphasised by many participants, consistent with previous findings (Chinn et al., 2014). Specifically, therapists perceived training as a source of guidance regarding their work, as well as a way to increase their confidence. However, many felt they lacked appropriate training and gaps in perceived knowledge and skills relevant to working with people with learning disabilities led many participants to feel ill-equipped for work with this group. Participants who had previously completed the IAPT high intensity training reported the adaptation of CBT for people with learning disabilities had not featured within their course curriculum, again consistent with previous findings (Chinn et al., 2014). The observation that nearly all therapists acknowledged a requirement for further training opportunities suggests that this is a gap which needs addressing.

People with learning disabilities represent a heterogeneous group (Rapley, 2004) and mainstream staff may feel ill-equipped to respond to their varied and complex mental health needs (Bouras & Holt, 2004). Training in delivering psychological

therapies to people with learning disabilities has been reported to be helpful by IAPT staff (Chinn et al., 2014; Dagnan et al., 2014) as well as leading to increased staff confidence (Dagnan et al., 2014; Mohr, Phillips, Curran & Rymil, 2008; Quigley, Murray, McKenzie & Elliot, 2001). This may support the observation that therapists with more training and experience reported higher confidence on the TCS-ID. Whilst it is not possible to infer firm conclusions, the high intensity therapist (Vicky) who did not have previous doctoral training reported the least confidence on the TCS-ID and described feeling particularly unconfident about work with people with learning disabilities. It may be that the competencies covered within psychology doctoral training, relating to working therapeutically with adults with learning disabilities, provides therapists with valuable skills and experience that is comparatively lacking within IAPT training. This may raise important considerations for IAPT workforces who have not completed clinical psychology training, and as such their need for further training may be even greater.

Therapist's confidence and perceived competence appeared to be central to participants' experiences, and some recognised training as a way of increasing their confidence related to the work, which reflects previous findings (Werner & Stawski, 2012). Consistent with other research (Dagnan et al., 2014) some participants described feeling more confident with relational aspects of the work, distinguishing between these items on the TCS-ID. This suggests that therapists did not experience difficulties with developing therapeutic relationships with clients with learning disabilities, but rather with technical aspects of delivering CBT to them. This corresponds with therapists perceiving a greater need for training to facilitate knowledge and skills development in adapting CBT, and with research indicating how specifically gaining greater knowledge about delivering therapy to people with learning disabilities can increase therapist confidence (Heneage et al., 2010). Specialist training has also been reported to increase IAPT therapists' confidence in work with older adults (Hilton, Law & Edgar, 2011), further suggesting the positive impact of training for IAPT staff. However, participants reported little opportunity for relevant training in working with people with learning disabilities and recognised low numbers of people with learning disabilities accessing the service as a potential barrier in services allocating necessary training resources. Given that training appears to be an important source of guidance in therapists' work, further training

opportunities are arguably justified. Low numbers of people with learning disabilities accessing IAPT may also limit the effectiveness of potential training, as therapists will have limited opportunity to apply and develop new skills (Bouras & Holt, 2004). Arguably, the lack of commitment paid to people with learning disabilities within IAPT may influence training opportunities, as indicated by Chinn et al. (2014). The paradoxical situation these barriers created was acknowledged by participants, who recognised that without training for therapists, it was unlikely IAPT would be able to meet the needs of people with learning disabilities.

Supervision was highlighted by participants as influencing the extent to which they felt able to respond to the complexities of working with people with learning disabilities. Specifically, specialist knowledge relevant to working with people with learning disabilities appeared an essential part of effective supervision. The educational process of CBT supervision has been previously highlighted (Prasko, Vyskocilova, Slepecky & Novotry, 2012; Pretorius, 2006), and specialist supervision has been identified as a central component in the delivery of effective therapy for people with learning disabilities within IAPT (Kirk et al., 2014). Specialist supervision regarding working with people with learning disabilities has also been reported to increase therapist skills and confidence (Salmon et al., 2013). The value of specialist supervision for IAPT staff working with specific groups has also been highlighted regarding older adults work (Hilton, Law & Edgar, 2011).

Supervision is considered instrumental in the development of therapists' skills and in ensuring the delivery of safe and effective psychological therapies within IAPT (Turpin & Wheeler, 2011). Jones (2013) has also highlighted the importance of effective supervision and reflective time in supporting therapists to manage the complex and time-consuming nature of working therapeutically with people with learning disabilities. When supervision was reported as being helpful by participants, it was described as providing guidance and a sense of certainty for therapists about their work, which may be particularly important when the work is considered challenging. Supervision was also seen as a way of increasing confidence related to working with people with learning disabilities. However, it appeared that clinical supervisors often lacked specialist knowledge regarding CBT for people with learning disabilities, arguably making it more difficult for them to provide therapists

with appropriate guidance and educational aspects related to their work. The lack of helpful supervision experienced by some participants is consistent with previous findings indicating supervision may offer IAPT staff little support regarding their work with people with learning disabilities (Chinn et al., 2014). Clinical supervisors within IAPT are expected to be familiar with issues of equality and diversity in delivering psychological therapies, including the IAPT Learning Disabilities Positive Practice Guide (Turpin & Wheeler, 2011). However, the limited awareness of the guide amongst participants suggests otherwise. Greater awareness of guidance is therefore clearly warranted.

#### 4.2.4 Evolving IAPT services

In line with previous research, the findings indicate that access issues have been largely unaddressed for people with learning disabilities within IAPT (Chinn et al., 2014). Under-representation in IAPT is not unique to people with learning disabilities; older adults also under-utilise IAPT services (Price, 2011). However, it appears that comparatively, these groups may receive more attention than people with learning disabilities, with the allocation of 'specialists' to these groups and adaptations, such as the use of interpreters, being implemented more readily than those required for people with learning disabilities (Chinn et al., 2014). Price (2011) draws attention to the catch-up role IAPT services have to adopt, in order to compensate for the limited consideration regarding the needs of diverse groups within the initial development of IAPT. Many therapists felt the complexities of working with people with learning disabilities were often poorly understood within IAPT. Some felt the inadequate attention paid to people with learning disabilities had resulted in the delivery of inappropriate processes and materials, including the MDS, consequently resulting in ethical dilemmas.

As a result of the challenges faced in their work, some participants reported feeling uncertain regarding the suitability of IAPT for people with learning disabilities. Of particular concern is how some therapists perceived IAPT to reinforce difficulties people with learning disabilities face in their everyday lives through the delivery of inappropriate processes and materials. Chinn et al. (2014) note how a social model



understanding of learning disability (Oliver, 1990) emphasises the duty of public services to address the socially created barriers experienced by this population. However, whilst therapists themselves may be sensitive to these issues, it appears that IAPT may be inadvertently reinforcing social barriers for people with learning disabilities. Jahoda et al. (2009a) noted that while evidence suggesting the effectiveness of CBT for people with learning disabilities may be assumed to generalise across contexts, the delivery of CBT may vary significantly across services. Participants reported finding it difficult to include broader social issues within the 'remit' of IAPT, considered crucial in making therapy meaningful and to avoid shifting attention away from broader social factors contributing to the cause of distress (Jahoda et al., 2009a). The IAPT context in which therapists are delivering CBT may make it difficult to make the necessary adaptations to therapy, thus possibly accounting for some of the challenges participants' alluded to.

On a national level, IAPT services aim to meet ambitious targets based on key performance indicators (KPIs), including number of individuals entering treatment and 'recovery rates', although they are not required to meet specific targets regarding people with learning disabilities. Price (2011) highlights how there may be little incentive for IAPT services to invest significant resources into increasing accessibility of services for groups who may be less likely to achieve high recovery levels. The ability of people with learning disabilities to 'fit in' with IAPT recovery expectations including the emphasis on paid employment, have been questioned previously (Chinn et al., 2014). Similarly, participants indicated that implicit within IAPT assessment is an evaluation of a client's ability to achieve recovery and some felt uncertain as to whether clients with learning disabilities fit this criterion. Furthermore, the use of existing KPIs to measure therapy outcomes may not be appropriate for people with learning disabilities (Kirk et al., 2014). Price (2011) suggests in relation to older adults that lowering KPI targets for this group may provide an incentive for services to focus resources on meeting their needs, and arguably this could also apply to targets relating to people with learning disabilities.

Related to service delivery, potential benefits associated with joint working between IAPT and local specialist learning disability services were indicated by participants and have been reported in the literature (Dagnan et al., 2013; Kirk et al., 2014;

Salmon et al., 2013). Partnership working may encourage greater collaboration between service systems, enabling services to share resource and expertise as well as endorse working within the National Service Framework for mental health; NSF DoH (1999) (Bouras & Holt, 2004), as outlined in the Green light toolkit (FPLD, 2004). However, difficulties with uniting services with contrasting models of working, namely IAPT's high volume, short-term interventions versus longer term MDS interventions typical of specialist learning disabilities services, have been highlighted (Salmon et al., 2013). This will therefore require careful consideration in future partnership working.

### **4.3 Implications and recommendations**

#### **4.3.1 Implications for practice and policy**

The qualitative nature of this study facilitated an in-depth exploration of high intensity therapists' experiences and enabled the collection of rich data using rigorous methods. Findings provide empirical evidence to inform practice and policy implementation as well as further research.

Related to clinical practice, therapists clearly require more specialist supervision. This may facilitate their confidence and skills development in delivering effective and appropriate formulation-driven adaptations and reasonable adjustments to people with learning disabilities. The improved circulation of a manual for CBT for people with learning disabilities by Hassiotis et al. (2013) may also offer a useful resource for therapists with their work. Individual performance targets need to be adjusted to permit therapists to work more flexibly with people with learning disabilities and to ensure they are able to safely and effectively respond to their needs. Developing more realistic expectations also relates to ensuring the emotional well-being of therapists. High workloads combined with a limited sense of autonomy have been linked with emotional exhaustion for IAPT workers (Steel, Macdonald, Schröder & Mellor-Clark, 2015).

More awareness amongst managers and supervisors regarding potential emotional exhaustion for IAPT therapists is required. This awareness may be developed through supervisors' training and this needs to inform how services operate. The emotional well-being of therapists may need to be considered and discussed within supervision and performance reviews, providing an opportunity for therapists to raise potential difficulties. The emotional demands of the work should also be considered when therapists' workload targets are agreed.

At a service level, IAPT may need to re-consider what constitutes appropriate reasonable adjustments for people with learning disabilities in order to ensure equitable access. Part of this will involve ensuring adapted versions of materials are easily accessible for therapists. Closer co-operation between specialist learning disability and IAPT services may facilitate the development of improved care pathways as well as offer training, resources and guidance. Greater awareness related to the needs of people with learning disabilities is required within IAPT, who need to have more of a presence in services. The allocation of a specialist in order to champion the needs of people with learning disabilities within services is suggested. More adjustments for therapists working with people with learning disabilities is also required to ensure they have adequate time to meet the demands of this service user group. This may also help to prevent emotional exhaustion and therapist burn-out.

On a national level, IAPT targets regarding people with learning disabilities accessing IAPT services need to be reviewed. This may encourage investment in service development for this service user group as well as develop consistency in the implementation of legislation and policy directives within IAPT. Relative to this, the use of the MDS with people with learning disabilities clearly requires further consideration.

The IAPT Learning Disabilities Positive Practice Guide (DoH 2009; 2013) recognises that therapists' confidence and concerns related to working with clients' vulnerability may present barriers in the delivery of CBT to people with learning disabilities in IAPT. There is an evident need to further consider the impact of these factors. Course curricula for both high intensity and supervisor training should include

material on the accessibility of CBT for people with learning disabilities to ensure therapists feel more confident regarding the work.

There is a clear need for a more developed evidence-base and increased understanding regarding the specific components of CBT for people with learning disabilities. However, in the interim clearer guidelines regarding flexible approaches to working with people with learning disabilities, specifically within IAPT, are required. The IAPT Learning Disabilities Positive Practice Guide (DoH 2009, 2013) is currently under review and the updated document will ideally address some of the issues highlighted in this study and provide services and therapists with increased clarity regarding the implementation of reasonable adjustments.

#### 4.3.2 Implications for further research

The current study builds on previous research (Chinn et al., 2014) by offering greater insight into the experiences of high intensity therapists delivering CBT to people with learning disabilities in IAPT, who may be most likely to work with this group when they access IAPT. Considering the experiences of this staff group may therefore be instrumental in increasing access to services for people with learning disabilities. Systematic evaluation is required to explore how effective CBT is for people with learning disabilities when delivered through IAPT. Further exploration of how therapists are making adjustments may also inform future service delivery.

This research has raised interesting areas of consideration regarding how clients may perceive IAPT therapy. Therapist, carer and service user perspectives of CBT for people with learning disabilities have been explored in previous research (e.g. Stenfert Kroese et al., 2013). Whilst these have provided useful insights into effective therapist and therapy components of CBT, further research is required to explore whether CBT delivered within the context of IAPT is perceived in a similar or contrasting light. The comparison of client and therapist experiences with outcome data may also offer further insight into how effective IAPT is for this group, although the selection of evaluation measures may need careful consideration. However, it is

acknowledged that the low numbers of people with learning disabilities accessing services may pose challenges for such research.

The benefits of training have been clearly highlighted. Further research into the effects of training for high intensity therapists regarding CBT for people with disabilities may offer useful insight into how IAPT may develop their services.

#### 4.3.3 Dissemination

The potential ways in which findings from this current study could be disseminated were considered in the early stages of the project. It was agreed with participating services that the researcher would return to each service to provide a feedback session that would include a presentation of the overall study findings and a short summary report. This study has highlighted that IAPT services may not be providing appropriate services to people with learning disabilities. The dissemination of findings will aim to increase awareness regarding the needs of people with learning disabilities and highlight any necessary reasonable adjustments. By addressing both therapists and team managers, who may be in a position of influence, it is hoped this will facilitate potential action. Providing a feedback session may also offer therapists an opportunity to raise concerns regarding access issues for people with learning disabilities with their management teams.

Further dissemination at an IAPT national conference has been agreed with the Foundation for Learning Disabilities. This will offer the opportunity to present findings to people with learning disabilities, IAPT professionals and commissioners. Dissemination has also been discussed with Professor Dave Dagnan, learning disabilities specialist, who is leading nationally in trying to put in place a positive and effective model of IAPT delivery for people with learning disabilities. This, along with possible publication, will aim to maximise the effects of dissemination in working towards increasing the accessibility of IAPT for people with learning disabilities.

#### **4.4 Critical evaluation of the research**

The quality assessment of qualitative research has been widely debated, and varying positions are held regarding how it should be evaluated (Spencer & Ritchie, 2012). However, Spencer and Ritchie (2012) suggest a number of guiding principles with which to assess research quality, including its contribution, credibility and rigour. These principles have been considered throughout this thesis report and some are further addressed within this section.

In consideration of the contribution of this research, this study echoed many previous findings, including those of a study conducted by Chinn et al. (2014), by suggesting that access issues have largely been unaddressed for people with learning disabilities in IAPT. This research extended current knowledge by providing a more in-depth exploration of the experiences of high intensity therapists delivering CBT to people with learning disabilities within IAPT. Many therapists reported feeling uncertain as to how to modify CBT for people with learning disabilities and as a result, they lacked confidence in making the necessary adaptations. They also appeared to have limited knowledge or an awareness of relevant literature. In addition to the complexities of adapting CBT for this population, organisational factors and the rigidity of the IAPT model appeared to present a number of additional challenges for therapists when attempting to make CBT more accessible. Whilst therapists identified a need for flexibility in approach, consistent with previous literature (e.g. Whitehouse et al., 2006), this appeared difficult in the context of IAPT. The lack of reasonable adjustments being made within IAPT services for people with learning disabilities raises many ethical issues in light of The Equality Act 2010, which warrant further consideration by IAPT services.

The thematic analysis employed within this study indicated a number of ways in which IAPT services may be developed to improve services for people with learning disabilities. Specific training has been shown to increase therapists' confidence regarding working with people with learning disabilities (Dagnan, 2013; Dagnan et al., 2014; Heneage et al., 2010). Findings indicated that therapists felt further training was required to support them with working with people with learning disabilities and perceived this a way to increase their confidence. Specialist supervision has

previously been identified as a key contributor to the delivery of effective IAPT services (Kirk et al., 2014), and this was also identified as an area of further need. This research also highlighted the emotional demands of the work. Therapists highlighted the challenges associated with managing the demands of high workloads and performance targets whilst working with people with learning disabilities in IAPT. These also require further consideration within services in order to ensure therapists are supported in their role of meeting the needs of people with learning disabilities within IAPT.

The credibility of this research, including how plausible and defensible the findings are, have been demonstrated through the detailed account of the data collection and analysis process as well as inclusion of raw data extracts. In consideration of research rigour, Spencer and Ritchie (2012) suggest that the defensibility, auditability and reflexivity of research should also be addressed. As such, descriptions and rationales for the choice of research design, methods and sampling strategies employed, and their relevance to the research aims have been documented within the methods section. The detailed account of the analysis process and examples of the coding audit trail within the appendices of this report addresses the auditability of this research. Reflexivity represents the other consideration of research rigour and is addressed in section 4.4.3. Further consideration of limitations will also be discussed.

It is noticeable that the data were heavily weighted towards challenges faced by the therapists in their roles. This finding is interesting by itself, and may suggest that therapists' roles are fraught with challenges. However, there may be other explanations for these findings, which will be considered.

First, participants reported little opportunity to reflect upon the complex issues they faced whilst working with service users with learning disabilities. The research interview process has been recognised to offer a validating and empowering experience for participants (Hutchinson, Wilson & Skodol Wilson, 1994), and may have presented therapists with a confidential forum to express their frustrations and dilemmas, which they may have little opportunity to do elsewhere. Interestingly,

during debriefing of interviews, nearly all participants reported enjoying the opportunity to talk about and reflect on the challenges of their roles.

Second, emphasis therapists placed on the challenges involved in their roles may be influenced by negativity bias. Haizlip, May, Schorling, Williams and Plews-Ogan (2012), in the context of academic medicine, reported an inherent bias for individuals to attend to and remember negative aspects of experiences. Furthermore, the problem-focused nature of discussions within services may have also encouraged therapists to emphasise the more negative aspects of their work.

As previously stated, many people with learning disabilities do not have a formal diagnosis, yet are likely to be accessing mainstream services. In consideration of this, along with the problematic nature of the diagnosis of learning disabilities, it was decided that therapists who had worked with people with suspected learning disabilities would also be included. This may have potentially impacted on the validity of this research. However, steps were taken to ensure participants were aware of the definition of learning disabilities, particularly how this may differ to learning difficulties. This included offering a definition of learning disabilities during team meetings or emails, as well as in the participant information sheet. At the start of each interview, participants were also asked to describe their clients' difficulties and severity to clarify that clients being discussed were service users with learning disabilities.

#### 4.4.1 Sampling and generalisation of findings

The current study has a number of limitations. Its design may have resulted in findings being influenced by a sampling bias. Participants were asked to express an interest in taking part in the research, potentially resulting in a particular type of individual being recruited. Arguably, individuals opting to take part in this study may hold stronger views about working with people with learning disabilities and may have a personal interest in this area. Consequently, this may not represent the experiences of all IAPT therapists working with this client group. Furthermore, the services that supported this project may represent those with a higher level of



commitment to developing the accessibility of IAPT for people with learning disabilities and thus influenced therapists' experiences. However, despite these possibilities, participants with a range of experiences and working contexts were recruited. In addition, the recruitment of participants required management approval within each IAPT service and whilst the identities of participating therapists remained confidential, this may have deterred some therapists from participating in the research. An alternative method of sampling, such as advertisement on professional on-line health and social care forums, independent of IAPT services and thus participants' employers may have removed some of these difficulties.

The time and resources available for this study limited the scale of the research. Whilst Guest et al. (2006) acknowledged difficulties of specifying the number of participants required within a research study, a larger sample size may have offered further support for identified themes within the analysis. Rather than aiming to achieve generalisation of findings, qualitative methods aim to develop understanding of complex phenomena (Marshall, 1996; Willig, 2008). However, recruiting participants across multiple IAPT services instead of a single service provided an enhanced overview and representation of therapists' experiences. Furthermore, findings from the present study map closely on to those reported by Chinn et al. (2014), suggesting many of the findings from the current study may be representative of a large proportion of IAPT services.

Ninety percent of the sample population had experience of doctoral level psychology training. Whilst recent figures regarding professional qualifications held by high intensity therapists are not available to provide comparison, previous figures (Aldridge & Duffy, 2009) suggest this sample may be more representative of London IAPT services, rather than the national IAPT workforce. Smaller numbers of clinical psychologists appear to be employed within IAPT workforces within other regions (Aldridge & Duffy, 2009). Doctoral level psychology training may provide valuable knowledge and skills related to working with people with learning disabilities, which therapists from other backgrounds, such as graduate mental health workers are less likely to possess. On this basis it may be assumed that IAPT workforces predominately consisting of clinical psychologists may be better equipped to deal

with the challenges involved with the work, compared to those who have fewer clinical psychologists, although this assumption is untested.

#### 4.4.2 Critical evaluation of the analysis process

Whilst many commonalities between the experiences of high intensity therapists were observable within the data, the chosen analysis may have inhibited understanding of the on-going process of sense making as well as differences between participants. Adopting an IPA approach may have better facilitated the illustration of the inherently different experiences of therapists in their role delivering CBT to people with learning disabilities. Consequently, this may have elicited the more specific details and understanding of individual therapists' unique experiences. However, of importance to this research was that the results were accessible to a wide audience, and that they were useful for informing policy development. Thematic analysis is considered a suitable method to achieve this (Braun & Clarke, 2012). Employing a thematic analysis within this research allowed key features of a rich data set to be summarised, including the commonalities and differences between participants' accounts.

Inter-rater reliability, which is under-pinned by a realist epistemological position, was not examined within this research. As this research adopted a critical position, which acknowledges the impact of the research upon the data analysis, multiple independent coders were not considered appropriate. Data collection, transcribing and analysis were completed by the researcher and transcripts were read only by the researcher, in line with ethical requirements. Coded data extracts were shared with the research supervisors, with whom the data analysis was discussed. This permitted a degree of quality assurance, whilst remaining congruent with a critical realist position.

#### 4.4.3 Researcher reflexivity

Reflexivity, including the researcher's reflections about the impact of their own identity, position and perspectives on the research process and data collected is considered an important part of assessing research rigour (Spencer & Ritchie, 2012). This position acknowledges that the process of analysis is iterative in nature and recognises the role of the researcher in the production of knowledge (Srivastava & Hopwood, 2009). As such, the analysis process is thought to involve a dialogue between the researcher and the data (Ritchie & Lewis, 2003). A reflective journal has facilitated on-going reflexivity throughout the research process and this current section aims to address the issue of reflexivity further, including the potential impact of the researcher upon the data collection and analysis process.

As indicated in chapter one, opinions amongst professionals appear divided regarding the appropriateness of IAPT for people with learning disabilities and my own position on this topic has inevitably shaped the process of this research. The selection and design of this study was motivated by my professional experiences and interest in advocating the accessibility of IAPT for people with learning disabilities. Whilst feeling optimistic about this mainstreaming agenda during the initial stages, I am aware that my position on this topic changed somewhat during the later stages of the project. As I became aware of some of the views held by IAPT management surrounding learning disabilities and of the challenges therapists were facing in their role, during the recruitment process and early interviews, I started to question the ability of some IAPT services to respond to the needs of this population. I was aware that I felt both curious and frustrated about this. As a result, it is possible that during data collection I may have attended more to participants' talk about the challenges they were experiencing in their role, particularly those related to organisational contexts (e.g. lack of managerial support). Journal extracts illustrating personal reflections on the process of the first and last interviews are included in Appendix 2.3 and Appendix 2.4. Whilst interviews provided opportunities for participants to talk about successes and positive experiences related to their work, the data were weighted more heavily towards challenges involved in the work. In hindsight the interview schedule could have included more explicitly framed positive

questions to assist with the exploration of these aspects of their role and as such, this may offer useful pointers for future research.

Upon reflection I noticed that participants elaborated less frequently on topics related to their confidence. Whilst not a central feature of my research, I wonder if I could have probed more into this area which may have facilitated greater insight regarding how this influenced participants' experiences. However, again, this may have been due to participants feeling this was not very relevant to their experiences. Related to this, the use of the TCS-ID hoped to facilitate exploration into therapists' confidence regarding their experiences of adapting CBT with people with learning disabilities within IAPT. Positively, the measure did encourage a focus on therapists' confidence within interviews, which appeared to be relevant to therapists' experiences and helped to situate the sample.

During the analysis phase of this study, I felt particularly aware of how my own position could be influencing the way I was interpreting the data. Reflecting on previous journal extracts from earlier stages of the research process was particularly helpful in considering how I had personally responded to the information I had gathered throughout the process. This allowed me to be aware of possible biases I held, particularly during the interpretative and coding stages of the research. Specifically, this allowed me to feel confident that I was also attending to the positives within the data. During the analysis phase of the research, it was also useful to reflect upon my own professional experiences. Having worked in both IAPT and learning disabilities services allowed me to consider the accessibility of IAPT for this group from two contrasting service contexts and helped me to consider factors related to both services. A reflective journal extract from the analysis phase is included in Appendix 2.5. All potential risk issues were

Following completion of the literature review for this present study, a report relevant to this study's research aim was published (Chinn et al., 2104). Whilst it would have been possible to revisit the time frame in which the literature review was conducted, the published study had not informed the design, data collection or analysis process of the present study. This, along with time constraints informed the decision not to include said report within the introductory chapter. A decision was also made by the

researcher not to consult findings reported by Chinn et al. (2014) prior to completion and reporting of data analysis. Whilst this study adopted a combined deductive and inductive approach to data analysis, it was recognised that the report may have had the potential to influence data analysis. Arguably, this offers a degree of reliability to the analysis and findings of this current study.

During interviews participants described a number of ethical dilemmas they faced whilst working with people with learning disabilities. It appeared that IAPT services were in violation of equality legislation regarding making reasonable adjustments for people with learning disabilities. Consequentially, this posed ethical dilemmas for the researcher. These were discussed within supervision, and careful consideration was given to possible action required. Potential risk issues were addressed as necessary with participants and no immediate risk issues were identified. It was felt that disclosing concerns to service managers prior to the write up and dissemination of the overall research findings may have jeopardised the anonymity of individual participants. The dissemination of the research findings were carefully considered in order to address these issues and it is hoped that findings will inform both clinical practice and policy.

## **4.5 Conclusion**

This thesis has presented a thematic analysis of high intensity therapists' experiences of delivering CBT to people with learning disabilities. The findings have emphasised the potential significance of both therapist factors, such as previous experience, knowledge and training and organisational factors on therapists' experiences of working with people with learning disabilities.

Many of the adaptations therapists described making to CBT for people with learning disabilities mapped closely to those previously highlighted within the literature. However, whilst some therapists reported successful aspects of therapy, many felt ill-equipped and lacked confidence in adapting CBT for people with learning disabilities. Participants appeared to have limited awareness of relevant policy and literature related to people with learning disabilities and described adopting a 'trial

and error' approach to delivering CBT for this service user group. Therapists highlighted a need for improved training and supervision to equip them with greater skills, support and confidence around delivering CBT to people with learning disabilities.

Participants alluded to a 'tokenistic commitment' to people with learning disabilities within IAPT, which appeared to impact on the consideration given to the accessibility of services for this client group and the resources available for therapists in their work. Whilst the potential challenges of adapting CBT for people with learning disabilities have been previously highlighted (e.g. Jahoda et al., 2009a), therapists also appeared to face additional challenges of making CBT accessible within the inflexible context of IAPT. This raises concerns regarding how well IAPT are responding to equality legislation (e.g. The Equality Act, 2010).

It is clear that the IAPT programme needs to consider how they can make the appropriate reasonable adjustments that are required for people with learning disabilities. Service agreements at commissioning level are needed to offer a more realistic framework to ensure equitable access.

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## 6. APPENDICES

### Appendix 1: Literature search details

#### 1. Literature search regarding CBT for people with learning disabilities

The following search terms were used to attempt to access literature surrounding cognitive behavioural therapy for people with learning disabilities. The key words and how they were used together with the Boolean operators 'AND' and 'OR' are shown below:

S1 "Intellectual disabilit\*"  
S2 "Learning disabilit\*"  
S3 "Developmental disabilit\*"  
S4 "Intellectual impairment"  
S5 "Mental retard\*"  
S6 "Mentally handicapped"  
S7 "Mental handicap"  
**S8 S1 or S2 or S3 or S4 or S5 or S6 or S7**  
S9 "Cognitive behav\* therapy"  
S10 "Cognitive therapy"  
S11 "CBT"  
S12 **S9 or S10 or S11**  
**S13 S8 and S12**

These search terms were used in the following databases: PsycINFO, PsychARTICLES, CINAHL Plus and Scopus. Limits applied to searches included Date: January 1980- September 2014; Language: English; Subject: Human.

A total of 1000 articles were identified using the above strategy. All titles were checked for relevance to people with learning disabilities and CBT, and where possible disregarded on the basis of title. Google Scholar and grey literature including conference presentations and unpublished work were searched using the terms to find additional relevant articles. Hand searches of relevant journals including Clinical Psychology Forum were also completed.

*Psych-info and psych-articles (via EBSCO) literature search results regarding CBT for people with learning disabilities*

Search number	Search criteria/ word	Number of articles
S1	"Intellectual disabilit**"	10,943
S2	"Learning disabilit**"	23,100
S3	"Developmental disabilit**"	22,073
S4	"Intellectual impairment"	588
S5	"Mental retard**"	28,390
S6	"Mentally handicapped"	1,469
S7	"Mental handicap"	2,361
S8	<b>S1 or S2 or S3 or S4 or S5 or S6 or S7</b>	63,282
S9	"Cognitive behav* therapy"	18,675
S10	"Cognitive therapy"	20,944
S11	"CBT"	8,164
S12	<b>S9 or S10 or S11</b>	30,802
S13	<b>S8 and S12</b>	412

*CINAHL Plus (via EBSCO) literature search results regarding CBT for people with learning disabilities*

Search number	Search criteria/ word	Number of articles
S1	"Intellectual disabilit**"	14,100
S2	"Learning disabilit**"	5,514
S3	"Developmental disabilit**"	6,925
S4	"Intellectual impairment"	157
S5	"Mental retard**"	2,291
S6	"Mentally handicapped"	293
S7	"Mental handicap"	345
S8	<b>S1 or S2 or S3 or S4 or S5 or S6 or S7</b>	24,415
S9	"Cognitive behav* therapy"	3,663
S10	"Cognitive therapy"	11,710
S11	"CBT"	2,000
S12	<b>S9 or S10 or S11</b>	12,808
S13	<b>S8 and S12</b>	177

*Scopus literature search results regarding CBT for people with learning disabilities*

Search number	Search criteria/ word	Number of articles
S1	"Intellectual disabilit**"	13,207
S2	"Learning disabilit**"	11,609
S3	"Developmental disabilit**"	19,008
S4	"Intellectual impairment"	10,284
S5	"Mental retard**"	46,191
S6	"Mentally handicapped"	1,655
S7	"Mental handicap"	1,359
S8	<b>S1 or S2 or S3 or S4 or S5 or S6 or S7</b>	84,849
S9	"Cognitive behav* therapy"	14,286
S10	"Cognitive therapy"	37,407
S11	"CBT"	9,212
S12	<b>S9 or S10 or S11</b>	44,151
S13	<b>S8 and S12</b>	411



## 2. Literature search regarding IAPT for people with learning disabilities

The following search terms were used to access literature regarding IAPT services for people with learning disabilities. The key words and how they were used together with the Boolean operators 'AND' and 'OR' are shown below:

- S1 "Intellectual disabilit\*"
- S2 "Learning disabilit\*"
- S3 "Developmental disabilit\*"
- S4 "Intellectual impairment"
- S5 "Mental retard\*"
- S6 "Mentally handicapped"
- S7 "Mental handicap"
- S8 **S1 or S2 or S3 or S4 or S5 or S6 or S7**
- S9 IAPT
- S10 "Improving access to psychological therapies"
- S11 "Increasing access to psychological therapies"
- S12 "PWP"
- S13 "Low intensity therapist"
- S14 "High intensity therapist"
- S15 **S9 or S10 or S11 or S12 or S13 or S14**
- S16 **S8 and s15**

These search terms were used in the following databases: PsycINFO, PsychArticles, CINAHL and Scopus. Limits applied to searches included Date: January 1980-September 2014; Language: English; Subject: Human.

A total of 14 articles were identified using the above strategy. All titles were checked for relevance to people with learning disabilities and CBT, and where possible disregarded on the basis of title. Google Scholar and grey literature including conference presentations and unpublished work were searched using the terms to find additional relevant articles. Hand searches of relevant journals including Clinical Psychology Forum were also completed.

*PsycARTICLES and PsycINFO (via EBSCO) literature search results regarding IAPT for people with learning disabilities*

Search number	Search criteria/ word	Number of articles
S1	"Intellectual disabilit**"	10,943
S2	"Learning disabilit**"	23,100
S3	"Developmental disabilit**"	22,073
S4	"Intellectual impairment"	588
S5	"Mental retard**"	28,390
S6	"Mentally handicapped"	1,469
S7	"Mental handicap"	2,361
S8	<b>S1 or S2 or S3 or S4 or S5 or S6 or S7</b>	63,282
S9	IAPT	108
S10	"Improving access to psychological therapies"	90
S11	"Increasing access to psychological therapies"	11
S12	"PWP"	36
S13	"Low intensity therapist"	1
S14	"High intensity therapist"	1
S15	<b>S9 or S10 or S11 or S12 or S13 or S14</b>	176
S16	<b>S8 and s15</b>	3

*CINAHL Plus (via EBSCO) literature search results regarding IAPT for people with learning disabilities*

Search number	Search criteria/ word	Number of articles
S1	"Intellectual disabilit**"	14,100
S2	"Learning disabilit**"	5,514
S3	"Developmental disabilit**"	6,925
S4	"Intellectual impairment"	157
S5	"Mental retard**"	2,291
S6	"Mentally handicapped"	293
S7	"Mental handicap"	345
S8	<b>S1 or S2 or S3 or S4 or S5 or S6 or S7</b>	24,415
S9	IAPT	104
S10	"Improving access to psychological therapies"	61
S11	"Increasing access to psychological therapies"	5
S12	"PWP"	33
S13	"Low intensity therapist"	0
S14	"High intensity therapist"	0
S15	<b>S9 or S10 or S11 or S12 or S13 or S14</b>	164
S16	<b>S8 and s15</b>	2

*Scopus literature search results regarding IAPT for people with learning disabilities*

<b>Search number</b>	<b>Search criteria/ word</b>	<b>Number of articles</b>
S1	"Intellectual disabilit**"	13,207
S2	"Learning disabilit**"	11,609
S3	"Developmental disabilit**"	19,008
S4	"Intellectual impairment"	10,284
S5	"Mental retard**"	46,191
S6	"Mentally handicapped"	1,655
S7	"Mental handicap"	1,359
S8	<b>S1 or S2 or S3 or S4 or S5 or S6 or S7</b>	<b>84,849</b>
S9	IAPT	271
S10	"Improving access to psychological therapies"	106
S11	"Increasing access to psychological therapies"	15
S12	"PWP"	727
S13	"Low intensity therapist"	0
S14	"High intensity therapist"	1
S15	<b>S9 or S10 or S11 or S12 or S13 or S14</b>	<b>1,045</b>
S16	<b>S8 and s15</b>	<b>9</b>

### 3. Literature search regarding therapist confidence in delivering CBT to people with learning disabilities

The following search terms were used to attempt to access literature surrounding therapist confidence in delivering CBT for people with learning disabilities. The key words and how they were used together with the Boolean operators 'AND' and 'OR' are shown below:

S1	"Intellectual disabilit*"
S2	"Learning disabilit*"
S3	"Developmental disabilit*"
S4	"Intellectual impairment"
S5	"Mental retard*"
S6	"Mentally handicapped"
S7	"Mental handicap"
<b>S8</b>	<b>S1 or S2 or S3 or S4 or S5 or S6 or S7</b>
S9	"Cognitive behav* therapy"
S10	"Cognitive therapy"
S11	"CBT"
S12	"Therapy"
S13	"psychotherapy"
<b>S14</b>	<b>S9 or S10 or S11 or S12 or S13</b>
S15	"Confidence"
S16	"Competence"
S17	"Training"
S18	"S15 or S16 or S17"
S19	"Therapist"
S20	"Practitioner"
S21	"Clinician"
S22	"Psychotherapist"
S23	"Staff"
<b>S24</b>	<b>S19 or S20 or S21 or S22 or S23</b>
<b>S25</b>	<b>S8 and S12 and S18 and S24</b>

These search terms were used in the following databases: PsycINFO, PsychArticles, CINAHL and Scopus. Limits applied to searches included Date: January 1980-September 2014; Language: English; Subject: Human.

A total of 733 articles were identified using the above strategy. All titles were checked for relevance to people with learning disabilities and CBT, and where possible disregarded on the basis of title. Google Scholar and grey literature including conference presentations and unpublished work were searched using the terms to find additional relevant articles. Hand searches of relevant journals including Clinical Psychology Forum were also completed.

*PsycARTICLES and PsycINFO (via EBSCO) literature search results regarding therapist confidence in delivering CBT to people with learning disabilities*

Search number	Search criteria/ word	Number of articles
S1	"Intellectual disabilit**"	10,943
S2	"Learning disabilit**"	23,100
S3	"Developmental disabilit**"	22,073
S4	"Intellectual impairment"	588
S5	"Mental retard**"	28,390
S6	"Mentally handicapped"	1,469
S7	"Mental handicap"	2,361
<b>S8</b>	<b>S1 or S2 or S3 or S4 or S5 or S6 or S7</b>	<b>63,282</b>
S9	"Cognitive behav* therapy"	18,675
S10	"Cognitive therapy"	20,944
S11	"CBT"	8,164
S12	"Therapy"	310,305
S13	"psychotherapy"	132,365
<b>S14</b>	<b>S9 or S10 or S11 or S12 or S13</b>	<b>375,411</b>
S15	"Confidence"	41,493
S16	"Competence"	42,956
S17	"Training"	214,703
<b>S18</b>	<b>S15 or S16 or S17</b>	<b>284,356</b>
S19	"Therapist"	37,218
S20	"Practitioner"	14,309
S21	"Clinician"	16,992
S22	"Psychotherapist"	5,022
S23	"Staff"	49,846
<b>S24</b>	<b>S19 or S20 or S21 or S22 or S23</b>	<b>117,515</b>
<b>S25</b>	<b>S8 and S14 and S18 and S24</b>	<b>274</b>

*CINAHL Plus (via EBSCO) literature search results regarding therapist confidence in delivering CBT to people with learning disabilities*

Search number	Search criteria/ word	Number of articles
S1	"Intellectual disabilit**"	14,100
S2	"Learning disabilit**"	5,514
S3	"Developmental disabilit**"	22,073
S4	"Intellectual impairment"	588
S5	"Mental retard**"	2,991
S6	"Mentally handicapped"	293
S7	"Mental handicap"	345
<b>S8</b>	<b>S1 or S2 or S3 or S4 or S5 or S6 or S7</b>	<b>24,415</b>
S9	"Cognitive behav* therapy"	3,663
S10	"Cognitive therapy"	11,710
S11	"CBT"	2,000
S12	"Therapy"	819,341
S13	"psychotherapy"	19,241
<b>S14</b>	<b>S9 or S10 or S11 or S12 or S13</b>	<b>827,069</b>
S15	"Confidence"	168,791
S16	"Competence"	50,800
S17	"Training"	101,932
<b>S18</b>	<b>S15 or S16 or S17</b>	<b>305,719</b>
S19	"Therapist"	8,621
S20	"Practitioner"	15,505
S21	"Clinician"	10,522
S22	"Psychotherapist"	690
S23	"Staff"	89,874
<b>S24</b>	<b>S19 or S20 or S21 or S22 or S23</b>	<b>122,896</b>
<b>S25</b>	<b>S8 and S14 and S18 and S24</b>	<b>121</b>

Search number	Search criteria/ word	Number of articles
S1	"Intellectual disabilit*"	13,210
S2	"Learning disabilit*"	11,609
S3	"Developmental disabilit*"	19,010
S4	"Intellectual impairment"	10,284
S5	"Mental retard*"	46,193
S6	"Mentally handicapped"	1,654
S7	"Mental handicap"	1,359
<b>S8</b>	<b>S1 or S2 or S3 or S4 or S5 or S6 or S7</b>	<b>84,854</b>
S9	"Cognitive behav* therapy"	14,295
S10	"Cognitive therapy"	37,409
S11	"CBT"	9,217
S12	"Therapy"	2,810,236
S13	"psychotherapy"	91,610
<b>S14</b>	<b>S9 or S10 or S11 or S12 or S13</b>	<b>2,852,778</b>
S15	"Confidence"	409,750
S16	"Competence"	183,725
S17	"Training"	613,128
<b>S18</b>	<b>"S15 or S16 or S17"</b>	<b>1,154,744</b>
S19	"Therapist"	46,954
S20	"Practitioner"	237,452
S21	"Clinician"	168,557
S22	"Psychotherapist"	8,566
S23	"Staff"	255,364
<b>S24</b>	<b>S19 or S20 or S21 or S22 or S23</b>	<b>679,582</b>
<b>S25</b>	<b>S8 and S12 and S18 and S24</b>	<b>338</b>

## **Appendix 2: Reflective journal extracts**

### **Appendix 2.1: Reflective journal extract during recruitment phase**

After contacting a number of service managers regarding my project, I have been disappointed to find that many IAPT services do not feel able, or want to participate in my research. Whilst understanding the time pressures IAPT services face, I have been disappointed about some service managers' opinions about my research and lack of enthusiasm about thinking about the accessibility of services for people with learning disabilities. A number of service managers have appeared to hold negative views towards the accessibility of IAPT for people with learning disabilities. One manager's comments particularly sticks in my mind, who stated that they did not personally believe IAPT was the most appropriate service for people with learning disabilities, and that other services were more suited. During this meeting, I noticed that my own reaction was one of frustration and anger about the lack of commitment from management to this population. I was surprised that one manager did not even know of the DoH IAPT Learning Disabilities Positive Practice Guide.

I wonder what impact it may have, if those representing IAPT in management do not feel this is a worthwhile topic to research, and whether this is an overall reflection of IAPT's focus on this area. I feel concerned that I will not recruit enough participants for this project in the timeframe. I have currently gained support from one IAPT service, but am aware that the low numbers of people accessing the service mean that few therapists within the service are likely to meet my inclusion criteria.

At the start of the project I positioned myself as an advocate for people with LD accessing IAPT services. However, I am aware that the process of recruitment has made me wonder about how much attention and focus services pay to making their services accessible for this group. I now wonder about the appropriateness of IAPT myself. I am mindful of my own reactions throughout this process and that these may influence the information I attend to more during the interview process. I realise that I may need to pay particular attention to not focusing more on negative experiences than positive experiences, based upon my negative encounters during recruitment. However, whilst feeling disappointment about some of the negative attitudes I have faced, some service managers have been more supportive towards my project and some are considering whether to participate. I still feel enthusiastic about the project and about talking to therapists about their experiences. I wonder whether they may feel differently about IAPT for people with learning disabilities, and am hopeful that they have had positive experiences of therapy with this client group.

### **Appendix 2.2: Reflective journal extract following pilot interview**

The completion of a pilot interview was a useful exercise in assessing the appropriateness of my interview schedule and my interviewing style.

During the interview I noticed how the respondent, at times, answered a question that I had intended to ask later on in the interview (as guided by my interview schedule). I observed how in some instances I closed down some of my participant's talk, possibly missing important details, in attempt to adhere to the order in which the questions appeared on my interview schedule. In supervision, and following re-reading of the transcript, I reflected how whilst following the interview schedule was necessary to guide the interview, it was also important to allow the free flow of conversation, in order to minimise the impact I had on the interview process.

I also reflected upon my tendency to probe further into areas that had resonated with my own areas of interests, and that I had at times neglected to question points I felt were perhaps more consistent with my own perspective. Through discussions with my supervisor, I also noticed that I had made some assumptions about the meaning of my interviewee's statements. I found this was particularly the case with some of the language often used in CBT. For example my participant had reflected how she had experienced the use of Socratic questioning to be difficult with people with learning disabilities. Having my own ideas about this concept through my own training and experience in CBT, I assumed that we shared the same understanding around what Socratic questioning involved. I thought about how in my next interview, I needed to be mindful about asking follow up questions in order to further my understanding about the participant's experience and extract the information I needed.

### **Appendix 2.3: Reflective journal extract following first interview**

Transcribing my first interview shortly after it took place, allowed me to reflect upon the interview process, including the impact I had on the process.

Through listening to the interview, I am aware that my questioning style seemed to be less neutral than I intended it to be. For example, when my participant spoke about the minimum data set outcome measures I asked them if they thought they were good and useful. Whilst the participant still appeared able to tell me that they felt they were "clunky", on reflection, I realise this may have been slightly leading. Perhaps a better question may have been to ask how my participant found the MDS, rather than asking them if they had found it useful.

I noticed that I felt particularly anxious during my first interview. On reflection, I think this was because I felt conscious of trying to get enough information from my participant and because I felt worried about placing extra time demands upon them, as I knew they were very busy. I wonder if this anxiety may have influenced my ability to focus as much as I would have liked. However, I feel my interview questioning was better since my pilot interview. During the interview I was mindful of trying not to make any assumptions about the meaning of my interviewee's statements, as I had done in the pilot interview. Through listening to my interview during transcribing, I have noticed that I successfully probed further with my participant to clarify points. This is something I felt I needed to improve on following my pilot interview. On one occasion, I asked my participant for clarification regarding the difference between step two and three interventions in IAPT when they



mentioned these, whereas I may have assumed I knew the difference during my pilot interview. Through clarifying this difference with the participant it also allowed further exploration of how they felt about the suitability of the different steps for people with learning disabilities, which may have been missed otherwise.

#### **Appendix 2.4: Reflective journal extract following last interview**

During the tenth interview, I found myself highly alerted to the ethical implications of people accessing IAPT – whether IAPT was able to respond to their needs, and noticed myself feeling frustrated towards IAPT services, based upon my participant's accounts of their experiences. Upon reflection, I feel this may have influenced how the conversation progressed at times, as I found it hard not to react to some of the extreme statements the participant was making. However, I feel keeping a reflective journal throughout the recruitment and interviewing stage has aided my awareness of my own feelings around the topic of research, which has been important in assessing how my objectivity may be impeded by my own values and beliefs. I feel this reflective process has been very valuable and I feel that it enabled me to notice the impact of my own views more, during the interview. As such, I felt I was able to pay more attention to my questioning style and I think this helped me to reduce the potential suggestibility of certain views towards my participant.

I felt that I had been able to develop a good rapport with my participant and I observed how at the start of the interview they had appeared slightly guarded, whilst towards the end of the interview they shared some more detailed information regarding some of the ethical dilemmas they had faced. Following the interview, I wonder if this is due to the participant feeling they could trust me more towards the end of our meeting, possibly from our developed rapport, or if I had subtly shared my own views about the comments they had made through non-verbal gestures and verbal cues therefore making them feel more comfortable about sharing their thoughts.

At the start of the interview, the participant spoke about a number of things, any of which could have been followed up (assessment issues, working with carers, complexity). I noticed myself feeling slightly overwhelmed at this point, feeling unsure which point to follow up. I decided to follow up their point about the therapeutic relationship, but I remember keeping a note in my head about all the points they had made and tried to come back to them at a later point, which I did. I feel that this skill is something I have learned through the course of my interviews and I don't feel I would have been so successful at this during the first couple of interviews. I also noticed that I felt more confident about what I was asking in probing questions which seemed to enable me to really enjoy the experience of this interview and attend more to the nuances of what my participant was saying.

I felt at times that it was difficult to keep the participant on topic, as they seemed to want to talk about their views about learning disabilities in general. I was aware of trying to keep on the topic of my research and felt I was more able to bring the conversation back to the topic of IAPT and learning disabilities more than I had been able to in previous interviews.

Upon reflecting on the interview I feel I may have attended more to my participants' comments around how therapy had not been successful, rather than the things that had gone well. I wonder if this was influenced again by my own reactions to some of the negative things they were saying, and my probes around these following my own interest in these points. In hindsight I feel I should have asked more about the successes to open up more opportunities for more positive talk

### **Appendix 2.5: Reflective journal extract during analysis**

#### Phase 3 of thematic analysis: Searching for Themes

The initial stages of data analysis have felt overwhelming at times; the data I have collected is very rich and detailed and participants seem to be saying many things within short extracts. It has felt difficult to code the richness of the data into 'labels' as outlined by Braun and Clarke (2006).

Having read and re-read the interview transcripts I am aware of my own reactions of feeling sympathetic towards the therapist I have interviewed, specifically regarding the many challenges they are facing in their difficult roles. I have been struck by the lack of support they appear to be receiving with their work and by the lack of commitment IAPT appears to hold towards people with learning disabilities. Having worked in both IAPT and learning disabilities services has allowed me a fortunate position; I feel able to empathise with both the perspectives of IAPT therapists who are managing challenging roles whilst working with people with learning disabilities, yet also remaining mindful of the position of learning disability services whose staff may feel uncertain and annoyed about the provision of services to this group and the often poor response to their needs. This further increases my sympathy for high intensity therapists who may be perceived by learning disability services as 'difficult'.

Having familiarised myself with relevant literature and engaged in reflexive practice throughout the project so far, I am very aware of the influence my position can have on how I may be interpreting the data. In reviewing my reflective journal from the various stages of the project, I am also mindful of how my own position has changed regarding people with learning disabilities accessing IAPT. Initially, I felt very positive about the mainstreaming initiative for people with learning disabilities and hopeful that IAPT may be appropriately adapting to the needs of this group. However, at this later stage I am doubtful that current services are able to respond appropriately to their needs. Having felt very aware of my own thoughts and position on this topic, I have tried to read the transcripts with an open and curious stance to allow me to also attend to the positives and successes reported by participants. This has helped me to ensure I am minimising the impact of my own biases upon the analysis process.

Moving from the large number of codes to developing and identifying a smaller number of themes have felt challenging. Specifically, I am conscious of losing the detail captured within the many codes I have identified so far. Supervision has been a useful resource in helping me to consider how codes may start to be grouped together by considering broad topics and commonalities between them. The creation

of a separate document in which I have collated codes and their associated extracts has facilitated this process and dealing with the large amount of data has started to feel more manageable. Again, I am constantly considering how I may be influencing the analysis and checking back to ensure that my codes are grounded in the raw data, which is helping me to feel confident that I am attending to my own influence within this process.

## Appendix 3: Participant Information sheet

### UNIVERSITY OF EAST LONDON

School of Psychology  
Stratford Campus  
Water Lane  
London E15 4LZ

**Project Title: The experiences of high intensity therapists delivering cognitive behavioural therapy to individuals with learning disabilities within IAPT services**

#### **Project Team**

The Principal Investigator:

Hayley Marwood, University of East London. Contact Details: [u1236136@uel.ac.uk](mailto:u1236136@uel.ac.uk)

Supervisory team:

Dr Deborah Chinn, NIHR Post Doctoral Research Fellow, Kings College London.

Dr Katrina Scior, Senior Lecturer & Academic Director of Doctorate in Clinical Psychology, University College London.

#### **Consent to Participate in a Research Study**

The purpose of this letter is to provide you with the information that you need to consider in deciding whether to participate in a research study. The study is being conducted as part of my Clinical Psychology Doctorate degree at the University of East London.

#### **Project Description**

The aim of this study is to explore the experiences of IAPT high intensity therapists delivering cognitive behavioural therapy (CBT) to clients with a learning disability.

'Learning disability' is a general term that refers to individuals who find it harder to learn, understand and communicate. This often affects a person's global functioning, and their ability to cope independently. It is different from a 'learning difficulty' which is used to refer to someone's significant learning problems in an academic area, and is mostly used in educational settings.

Participants will need to have delivered CBT to **at least one client with a learning disability** within an IAPT service.

#### **Your involvement**

The project will involve an interview with the researcher, and will include questions about your experiences of delivering CBT to clients with learning disabilities, about your thoughts regarding how effective therapy has been, and about your views of your own training and support needs within this area. It will also involve you completing a short questionnaire about your confidence around delivering therapy to people with learning disabilities. Completion of this questionnaire will take approximately 10 minutes. You will be asked complete this before your interview, so that we can talk about it in our meeting.

The finished research will be in the form of an academic thesis. The researcher may use the research data to write articles to be submitted for publication in academic or practice journals.

#### **Confidentiality of the Data**

Your interview will be with the researcher, Hayley Marwood. It will be recorded on a digital recording device, and then copied to a password protected disc which only the researcher will have access to. Recordings will be deleted from the recording device. Interview recordings will be typed in to transcripts. Any names that are mentioned will be anonymised to protect confidentiality. Our conversation will be private unless I am worried that there is risk of serious harm to someone in which case I would have to talk to someone else.

The anonymised transcripts may be read by the research supervisors, or by the examiners who assess this thesis project. No one else will have access to the transcripts, and they will be saved on a password protected computer. Following examination, all recordings will be destroyed. Written transcripts will be kept on a password protected computer file for five years, and may be used for additional articles or publications based on the research.

Research findings will be shared with participating IAPT services, NHS trusts and national IAPT leads, and may be disseminated in subsequent publications. Findings will not be broken down by Trust or service in order to protect participant anonymity. The final research article will include a small number of quotes taken from participant interviews. Names and identifying features will be altered in transcripts, thesis extracts and future publications to protect anonymity.

#### **What are the benefits of taking part?**

I hope that you will find taking part in this research interesting. It will provide you with an opportunity to share your views and experiences of working with clients with learning disabilities in IAPT. It is hoped that this research will contribute to developing our understanding of how people with learning disabilities are currently accessing mainstream services, and lead to service developments.

#### **What are the risks of taking part?**

As we will be discussing your experiences and views about working with people with learning disabilities in IAPT within your professional role, it is unlikely that there any risk of harm to you or others. If you do find any part of the interview uncomfortable or upsetting you can let me know if you would prefer not to answer a question, or if you would like to end the interview. I can then let you know of places you can access for more support.

#### **Location**

Interviews will take place at your place of employment, or in a location of your choice, where confidentiality can be maintained.

#### **Disclaimer**

You are not obliged to take part in this study and should not feel coerced. You are free to withdraw at any time. Should you choose to withdraw from the study you may do so without disadvantage to yourself and without any obligation to give a reason. Should you withdraw, the researcher reserves the right to use your anonymised data in the write-up of the study and any further analysis that may be conducted by the researcher.

Please feel free to ask me any questions. If you are happy to continue you will be asked to sign a consent form prior to your participation. Please retain this invitation letter for reference.

If you have any questions or concerns about how the study has been conducted, please contact the study's supervisor Kenneth Gannon, School of Psychology, University of East London, Water Lane, London E15 4LZ. Telephone. Email address

**or**

Chair of the School of Psychology Research Ethics Sub-committee: Dr. Mark Finn, School of Psychology, University of East London, Water Lane, London E15 4LZ.  
(Tel: [REDACTED]. Email: m.finn@uel.ac.uk)

Thank you in anticipation.  
Yours sincerely,

Hayley Marwood  
28 February 2014

## **Appendix 4: Email sent to IAPT staff teams**

Dear Colleagues,

I am hoping to enlist your support for a study into IAPT for people with learning disabilities.

As you are probably aware, the expectation that people with learning disabilities should access mainstream services wherever possible, including IAPT services, has led to many debates about the appropriateness of this. Leading on from very recent research, one gap I have identified in the literature is a need to gain a better understanding of the experiences of IAPT therapists who have provided therapy to people with LD, including their experiences of adapting their approach, their awareness of national guidance and best practice, and views of their own training and support needs.

I am hoping to conduct research to sensitively develop a picture of the experiences and needs of high intensity therapists delivering CBT to people with learning disabilities. This can be either within your current role, or within another IAPT service you have worked in. Client work could be anything from an assessment session to completed/ uncompleted therapy sessions. I would be interested in talking to all staff including unqualified therapists who are delivering high intensity therapies. Clients would not necessarily need to have a formal diagnosis of learning disabilities, as I recognise there are many people who may have an undiagnosed LD. This research will be undertaken as part of my clinical psychology doctorate training at the University of East London. All relevant ethical approval from the University and the NHS has been obtained.

Data collection would involve completion of a very brief measure to assess therapist's confidence in seeing people with LD, followed by a 1-off interview of about 50-60 minutes. So far, feedback from participating therapists has been that it has been a positive and useful experience.

I appreciate that you are all extremely busy, so I would ensure that your time would be kept to a minimum. Interviews would be arranged at a time and place to suit your convenience.

I have attached an information sheet on my research for your reference. If you feel you may be able to participate in this study and wish to discuss it further with me, I would really value your time.

Kind Regards,

Hayley Marwood

Trainee Clinical Psychologist  
Professional Doctorate in Clinical Psychology  
University of East London  
U1236136@uel.ac.uk

## **Appendix 5: Information covered during presentations to IAPT service team meetings**

- Introduce self
- Background to the research

People with LD are being encouraged to access mainstream services, including IAPT services – and services are beginning to think about how they might adapt their current service to meet the needs of this client group. This is based on key legislation surrounding improving services for people with learning disabilities.

An evidence-base is beginning to develop for the use of CBT with people with learning disabilities.

At the moment, it seems that different services are offering different therapy provision to people with learning disabilities and it's unclear how they are getting on, particularly how therapists delivering CBT to people with learning disabilities are finding it. I am interested in finding out about the experiences of therapists delivering CBT to people with LD.

### **• Recruitment**

High intensity therapists who have delivered CBT to at least one person with learning disabilities, within an IAPT service.

### **• Defining learning disabilities**

'Learning disability' is a general term that refers to individuals who find it harder to learn, understand and communicate. This often affects a person's global functioning, and their ability to cope independently. It is different from a 'learning difficulty' which is used to refer to someone's significant learning problems in an academic area, and is mostly used in educational settings.

I am interested in people with 'learning disabilities', rather than people who experience learning difficulties such as dyslexia, dyspraxia etc. They do not necessarily need to have a formal diagnosis of LD as many people are thought to be undiagnosed. As long as you suspect they do, or the GP or other referrer has queried it.

### **• Involvement**

I am aware that you all hold busy roles, and have limited time to spare. I am very mindful of this and will only conduct one-off interview lasting about 50-60 mins, along with a very brief questionnaire (taking approx. 5 mins). This would be conducted at a time and location to suit you.

The interview will involve me asking you questions about your experiences – particularly about the things that seemed to go well as well as the things that were challenging. You don't need to worry about remembering specific details about the client(s) you worked with, as I am really interested in your views and thoughts about the delivery of CBT to people with LD and the support and training needs you feel might be needed.

I am hoping to recruit HI therapists from a number of different services. Data collected from interviews will be reviewed, and I will be using a type of analysis that will allow me to develop some common themes across the data.

The findings will hopefully be used to provide insight into what is working well, as well as challenges and barriers to providing accessible and effective therapy to these clients. It will hopefully provide areas of recommendation for service development as well as staff training and support needs.

- **Benefits**

I would hope that it would be a positive experience, allowing you to talk about and give your views about the subject, and contribute to service recommendations to help improve services for both service users and staff.

- **Confidentiality**

All information that you tell me will remain confidential. This research will be written up as part of my thesis. I intend to provide all participating services with a summary report of my overall research findings, as well as recommendations based on these findings.

In the write up of my research, I will need to include extracts from interviews. However, I would ensure that these are anonymous, and would not include any identifiable information to ensure individual participants are not identifiable.

Research findings will also not be broken down by trust to protect participant confidentiality.

- **Contact**

I will be leaving an information sheet about my research project, which has my contact details on if you would like to participate, or talk to me further about it.



## Appendix 6: Participant Consent form

### UNIVERSITY OF EAST LONDON

#### Consent to participate in a research study

##### Title of Study:

The experiences of high intensity therapists delivering cognitive behavioural therapy to individuals with a learning disability within IAPT services

Chief Investigator: Hayley Marwood

I have read the information sheet relating to the above research study and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.

Please initial

I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. Only the researcher(s) involved in the study will have access to identifying data. It has been explained to me what will happen once the research study has been completed.

Please initial

I consent to the audio recording of my interview, which will be used to create anonymised transcripts and then destroyed following examination of this research. I also consent to direct quotes being taken from my interview and used in any write-ups of this research. All transcripts and quotes will be anonymised to protect confidentiality.

Please initial

I hereby freely and fully consent to participate in the study which has been fully explained to me. Having given this consent I understand that I have the right to withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason. I also understand that should I withdraw, the researcher reserves the right to use my anonymous data in the write-up of the study and in any further analysis that may be conducted by the researcher.

Please initial

Participant's Name (BLOCK CAPITALS).....

Participant's Signature.....

Researcher's Name (BLOCK CAPITALS) .....

Researcher's Signature.....

Date: .....

## Appendix 7: Interview schedule

### Interview Schedule

#### Introductions

Tell me about yourself

#### Experiences of working with people with learning disabilities

In present role or in other contexts

- |                                  |
|----------------------------------|
| Prompts                          |
| • Tape recorder                  |
| • Consent                        |
| • Follow up TCS-ID questionnaire |

#### Could you tell me about a client you have worked with in an IAPT service who had a learning disability?

Prompts:

- **Severity** of Learning disability? Presentation?
- **Referral process** – barriers to access? How does your organisation manage referrals, eligibility criteria?
- **Assessment Process** – Adapted materials? – details (why, how)
- **Before** – expectations, concerns, preparation, confidence – link to TCS-ID – how did this affect you?
- **During** - What worked well using a CBT approach? Not so well?
  - Process** – engagement? Collaborative relationship? Attendance? Differences/ similarities? Communication difficulties?
- Did the experience of working with this client fit with prior expectations?

#### Did you need to make any adaptations to CBT with this client?

Prompts

- **What adaptations** (session length, materials), **Why, How?** did you use the literature base to guide you?
- What effect did they have?
- How flexible were you able to be? Did you feel supported by management?

#### Do you know of the IAPT Positive Practice Guidance on working with people with learning disabilities?

Prompts:

- Applicability and usefulness?
- Are there clear **service agreements** for the provision of people with learning disabilities? – Expectations of the service and of the staff?
- **Training** from LD services?
- How well supported do you feel – supervision?

#### Did you include carers in therapy with this client?

Prompts:

If yes,

- How, Why? Was it difficult to manage?
- Benefits/ disadvantages of including them?

If no,

- Reasons? Do you think it would have been appropriate?
- Did the client actively decide not to
- Any practical reasons why they weren't included? (room size, availability).

Did you feel it was necessary to attend to more contextual issues compared to other clients? (explain)

#### How have you measured therapy outcomes?

Prompts:

- Did the **results reflect your views/ the clients view** of therapy outcomes?
- Was there anything you feel **impacted on therapy outcome**?
- What was the ending of therapy like- experience of covering relapse prevention?
- Did you or the clients have concerns about the long term utilization of skills? If so, why?

Ask about another client that didn't work so well/ worked well depending on first example.

**Anything else** **Ending**

Reminder about confidentiality

## Appendix 8: UEL ethical approval

### SCHOOL OF PSYCHOLOGY

Dean: Professor Mark N. O. Davies, PhD, CPsychol, CBiol.



### School of Psychology Professional Doctorate Programmes

To Whom It May Concern:

This is to confirm that the Professional Doctorate candidate named in the attached ethics approval is conducting research as part of the requirements of the Professional Doctorate programme on which he/she is enrolled.

The Research Ethics Committee of the School of Psychology, University of East London, has approved this candidate's research ethics application and he/she is therefore covered by the University's indemnity insurance policy while conducting the research. This policy should normally cover for any untoward event. The University does not offer 'no fault' cover, so in the event of an untoward occurrence leading to a claim against the institution, the claimant would be obliged to bring an action against the University and seek compensation through the courts.

As the candidate is a student of the University of East London, the University will act as the sponsor of his/her research. UEL will also fund expenses arising from the research, such as photocopying and postage.

Yours faithfully,

Dr. Mark Finn

Chair of the School of Psychology Ethics Sub-Committee

Stratford Campus, Water Lane, Stratford, London E15 4LZ  
tel: +44 (0)20 8223 4966 fax: +44 (0)20 8223 4937  
e-mail: mno.davies@uel.ac.uk web: www.uel.ac.uk/psychology



The University of East London has campuses at London Docklands and Stratford  
If you have any special access or communication requirements for your visit, please let us know. MINICOM 020 8223 2853



(Attachment to letter)

**RESEARCHER RISK ASSESSMENT CHECKLIST (BSc/MSc/MA)**

**SUPERVISOR:** Kenneth Gannon

**ASSESSOR:** Christian Van Nieuwerburgh

**STUDENT:** Hayley Marwood

**DATE (sent to assessor):** 20/02/2014

**Proposed research topic:** The experiences of high intensity therapists delivering cognitive behavioural therapy to individuals with learning disabilities within IAPT services.

**Course:** Professional Doctorate in Clinical Psychology

Would the proposed project expose the researcher to any of the following kinds of hazard?

- |    |  |    |
|----|--|----|
| 1  | Emotional                              | NO |
| 2. | Physical                               | NO |
| 3. | Other<br>(e.g. health & safety issues) | NO |

If you've answered YES to any of the above please estimate the chance of the researcher being harmed as: HIGH / MED / LOW

**APPROVED**

	YES, PENDING MINOR CONDITIONS	
--	-------------------------------	--

**MINOR CONDITIONS:**

Researcher should liaise with supervisor about the location of the interviews once the NHS Trusts have been selected, in order to ensure that these take place in appropriate locations (to ensure that the researcher is not exposed to any hazards).

Once this has been discussed with the supervisor, the researcher can proceed without further reference to the ethical committee.

**REASONS FOR NON APPROVAL:**

Assessor initials: **CJvN** Date: 27 February 2014

For the attention of the assessor: Please return the completed checklists by e-mail to [ethics.applications@uel.ac.uk](mailto:ethics.applications@uel.ac.uk) within 1 week.

## **Appendix 9: Email documentation confirming fulfilment of UEL ethical amendments**

### **RE: UEL ethics**

Kenneth Gannon

**Sent:** Wednesday, February 25, 2015 9:21 AM

**To:** Hayley MARWOOD

Dear Hayley

I think that I may have omitted to send you a reply to this message. My sincere apologies if I did.

I am satisfied with your response to the comments from the reviewer of your application for ethical approval and feel that you have addressed the issue relating to your personal safety.

Please retain a copy of this email and insert it into your thesis to accompany the ethical approval.

Best wishes,  
Ken

Dr Kenneth Gannon  
Research Director  
Professional Doctorate in Clinical Psychology

**From:** Hayley MARWOOD

**Sent:** 07 November 2014 10:41

**To:** Kenneth Gannon

**Subject:** UEL ethics

Dear Ken,

Further to our discussions regarding my UEL ethics amendments, I have decided that all interviews will take place within participant (IAPT staff) dedicated working areas, during IAPT working hours. All interviews will be conducted in a private room where confidentiality can be maintained.

Best wishes,

Hayley

Hayley Marwood  
Trainee Clinical Psychologist  
University of East London  
[u1236136@uel.ac.uk](mailto:u1236136@uel.ac.uk)

## Appendix 10: NHS R&D approval letters (Three R&D approval letters)



Miss Hayley Marwood  
Department of Psychology  
University of East London  
Water Lane  
London EL5 4LZ

23 September 2014

Dear Miss Marwood

**Re: The experiences of high intensity therapists delivering cognitive behavioural therapy to individuals with learning disabilities within IAPT services**

**LREC Ref:**

**R&D Reference Number: MARHW1401**

I am pleased to confirm that the above study has now received a full R&D approval, and you may continue your research in **West London Mental Health Trust**. May I take this opportunity to remind you that during the course of your research you will be expected to ensure the following:

- **Patient contact:** only trained or supervised researchers who hold the appropriate Trust/NHS contract (honorary or full) with each Trust are allowed contact with that Trust's patients. If any researcher on the study does not hold a contract please contact the R&D office as soon as possible.
- **Informed consent:** original signed consent forms must be kept on file. A copy of the consent form must also be placed in the patient's notes. Research projects are subject to random audit by a member of the R&D office who will ask to see all original signed consent forms.
- **Data protection:** measures must be taken to ensure that patient data is kept confidential in accordance with the Data Protection Act 1998
- **Health & safety:** all local health & safety regulations where the research is being conducted must be adhered to.
- **Serious Adverse events:** adverse events or suspected misconduct should be reported to the R&D office and the Research Ethics Committee.
- **Project update:** you will be sent a project update form at regular intervals. Please complete the form and return it to the R&D office.
- **Publications:** it is essential that you inform the R&D office about any publications which result from your research.
- **Ethics:** R&D approval is based on the conditions set out in the favourable opinion letter from the Research Ethics Committee. If during the lifetime of your research project, you wish to make a revision or amendment to your original submission, please contact both the Research Ethics Committee and R&D Office as soon as possible.
- **Monthly/Annual Progress report:** you are required to provide us and the Research Ethics Committee with a progress report and end of project report as part of the research governance guidance.
- **Recruitment data:** if your study is a portfolio study, you are required to upload the recruitment data on a monthly basis in the website:  
<http://www.westlondonmentalhealthtrust.nhs.uk/our-services/our-services/portfolio/a-recruitment/>
- **Amendments:** if you need to make an amendment to your study, please contact the Research Ethics Committee. Once they have responded, and confirmed what kind of amendment it will be defined as, please contact the R&D office and we will arrange R&D approval for the amendment.
- **Audits:** each year, West London Mental Health Trust selects 10% of the studies from each service we have approved to be audited. You will be contacted by the R&D office if your study is selected

for audit. A member of the governance team will request you complete an audit monitoring form before arranging a meeting to discuss your study.

We would like to wish you every success with your project.

Yours sincerely



Trust Headquarters, West London Mental Health NHS Trust, Hybridge Road, Southall, UB4 2EH  
A solid black rectangular box used to redact the contact information, likely a phone number or email address.



02 May 2014

Hayley Marwood  
Department of Psychology  
University of East London  
Water Lane  
EL5 4IZ

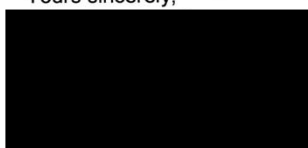
Dear Hayley Marwood

I am pleased to confirm that the following study has now received R&D approval, and you may now start your research in **the trust(s) identified below**:

<b>Study Title:</b> The experiences of high intensity therapists delivering cognitive behavioural therapy to individuals with learning disabilities within IAPT services. <b>R&amp;D reference:</b> 148978 <b>REC reference:</b> n/a		
This NHS Permission is based on the REC favourable opinion given on <b>n/a</b> and the most recent amendment submitted to REC on <b>n/a</b>		
<b>Name of the trust</b>	<b>Name of current PI/LC</b>	<b>Date of permission issue(d)</b>
		02 May 2014
If any information on this document is altered after the date of issue, this document will be deemed INVALID		

<b>Specific Conditions of Permission (if applicable)</b>
If any information on this document is altered after the date of issue, this document will be deemed INVALID

Yours sincerely,



Cc: Principle Investigator(s)/Local Collaborator(s), Sponsor Contact

R&D approval letter, REC reference: n/a, R&D reference: 148978

27 March 2014

Hayley Marwood  
Department of Psychology  
University of East London  
Water Lane  
EL5 4LZ

Dear Hayley Marwood

I am pleased to confirm that the following study has now received R&D approval, and you may now start your research in **the trust(s) identified below:**

<b>Study Title:</b> The experiences of high intensity therapists delivering cognitive behavioural therapy to individuals with learning disabilities within IAPT services. <b>R&amp;D reference:</b> 148978 <b>REC reference:</b> n/a		
This NHS Permission is based on the REC favourable opinion given on n/a and the most recent amendment submitted to REC on n/a		
<b>Name of the trust</b>	<b>Name of current PI/LC</b>	<b>Date of permission issue(d)</b>
		27 March 2014
If any information on this document is altered after the date of issue, this document will be deemed INVALID		

<b>Specific Conditions of Permission (if applicable)</b>  
If any information on this document is altered after the date of issue, this document will be deemed INVALID

Yours sincerely,



Cc: Principle Investigator(s)/Local Collaborator(s), Sponsor Contact

R&D approval letter, REC reference: n/a, R&D reference: 148978

## Appendix 11: Transcription conventions used

<b>P</b>	Indicates participant
<b>I</b>	Indicates interviewer
<b>( )</b>	Indicates pause in speech
<b>[unclear]</b>	Indicates speech was unclear
<b>[ ]</b>	Indicates when a comment has been added by the author e.g. [someone enters the room/ brief interruption] or [P1 laughs]
<b>&lt; &gt;</b>	Indicates interruption
<b>/</b>	Indicates overlapping speech
<b>-</b>	Indicates unfinished word.

Adapted from Parker (2005)

Parker, I. (2005). *Qualitative Psychology: Introducing Radical Research*. Berkshire, England: Open University Press.

## Appendix 12: Extract of annotated transcript

P4

Uncertainty around how the work should go	492 493 494 495	with them means that um I feel um err a kind of adequate with what I'm doing even though it may [unclear] that's look but they're not making as much progress so I think it's the same with learning disabilities I think that if I had the right kind of sense in mind of how	Not knowing where to pitch it
Needing to feel adequate? Work looks different? Different to working with mainstream population increased complexity? clearer idea about what work should look like	496 497 498 499 500 501 502 503 504	the work should go and the progress they should what is the progress and what should it be then that would help me work with them if that makes sense I: yeah it does yeah so what what kind of knowledge and skills do you think you would need or a therapist would need what within IAPT P4: I think case examples would be really useful um and what the interven- yeah what what the treatment looked like would be really great err what the typical type of problems and how those problems are resolved um	Uncertainty about the work Need for more Training - (case examples) Not knowing where to pitch No training in LD.
(Idea work should look a certain way)	505 506 507 508 509	I: have you had any training P4: no I: not sort of whilst you've been here and is that something that you feel like would be quite important to have P4: yeah	
Want More Training Barriers to Training? Nothing Available Currently a lack of guidance available - Not on Agenda, Not in practice	510 511 512 513 514 515 516 517	I: /yeah/ P4: /yeah/ I mean even if even if there was something that was written that could be read um that would be really useful <I: yeah>/um/ because I don't see enough people with learning disabilities to then do like a week's worth of training maybe a day's training could be useful um but even so I think maybe something just a a good article on what to do with patients in an IAPT service <I: yeah> um would be really helpful	LD missing in practice: Poor guidance available Resource investment not worth while More Guidance needed
Needing to be doing a 'good job' Difficult to tell?	518 519 520 521 522 523 524 525 526 527 528	I: so if you um say I don't know if you were able to to design a training um package for you and um the people that you worked with in this service /<P4: mmm>/ /IAPT/ therapists working with people with learning disabilities what kind of what would it look like what /<P4: um>/ /kind of things/ would it include P4: well obviously just what I said /<I: yeah>/ case/ examples <I: mm hmm> um typical types of problems that occur how to manage those problems kind of expectations for um how to assess whether you're doing a good job with that person if that makes sense I: yeah <P4: yeah> is that something that you find you quite difficult to find to to assess how therapy's going	Need For Training Training - Case examples Uncertainty about the work More guidance needed

14 of 26 - clearer idea of work

Currently unsure  
about the work

529 P4: yeah

530 I: yeah

Uncertainty about the  
work

MDS -  
unhelpful  
Not Suitable

531 P4: yeah so to well yeah to to know what the um what I suppose  
532 what the goal is with that person <I: mmm> you know

Uncertainty about  
Client's goal for therapy

533 I: yeah so how have you assessed um how it's going

MDS Inappropriate

534 P4: well we have the minimum data set which I don't think's very  
535 helpful err well no I [sighs] um /and/ /<I: what does>/ <I: sorry> yeah  
536 minimum what is it um it's just um questionnaires that patients fill  
537 out every session PHQ-9 is a nine question depression itemised  
538 and then the GAD-7 is seven um err questions and then there's a  
539 work and social adjustment <I: okay> scale as well

MDS Demanding  
(For Client & Therapist)

540 I: so have you used those with people with LD

Reliability of Questionnaires  
questioned

541 P4: in thinking about it I don't think they really understood it I mean  
542 this is it [points to minimum data set] so it's it's not very um friendly I  
543 suppose

544 I: why do you think they struggled with it /from your experience/

Confusion for Clients  
Needing help to  
understand

545 P4: /err/ well it just I suppose confidence with reading um the words  
546 are quite small it it's quite basic language but most people get stuck  
547 on this work and social adjustment just because it's I don't know  
548 slightly confusing um

MDS Demanding/  
inappropriate

549 I: so did they struggle with it

550 P4: yeah well I mean they circled she circled it whether she was  
551 reading it or not is another question

Reliability of MDS  
Uncertain

Lack of Reasonable  
Adjustments?

552 I: yeah so in your opinion would do you think they're suitable

553 P4: probably not I'd say yeah

Having to use MOS  
Even though can  
see it's not useful/  
Suitable  
No-Autonomy?

554 I: and d- did you use any other specialist um measures for that have  
555 been used developed for /<P4: no/ /use/no

MDS inappropriate for  
people with LD

556 P4: no

No other specialist  
measures used

557 I: and would that be something that I- that your IAPT service would  
558 do or perhaps

No Diagnosis is  
Tricky

559 P4: yeah I mean it's again it's tricky with someone who's not  
560 diagnosed with a learning disability to so it's about whether the  
561 clinician kind of picks up on and gets a sense that that person's  
562 having difficulty um in terms of then how they um adapt the work  
563 that they're doing

Uncertainty about clients  
abilities /understanding  
(Increased Complexity)

Reliance upon therapists  
ability to detect disability

15 of 26

Knowledge / Experience  
of Therapist Critical

		P4	Unhelpful Supervision
Feeling uncertain about the work, but not using literature?	564 I: yeah and in terms of um sort of what you've used to guide what 565 you've been doing cos you've said that maybe <u>the supervision hasn't</u> 566 <u>been quite as useful as you would have liked</u> um do you use any 567 literature or policies to guide the work	No use of Policy / Literature in Work	
Time restraints preventing looking?	568 P4: /no/ 569 I: /no/ no and are you aware of um cos I think there's um a policy the 570 IAPT positive practice guideline for people with learning disabilities 571 /<P4: no>/are/ you aware of that um and so you've not sort of used 572 much literature it's mainly been kind of supervision yeah	Unaware of IAPT LD Positive Prac' Guide	
Unhelpful / Simple advice given - Not translating to practice	573 P4: yeah [yawns] 574 I: um and when they said kind of to do more behavioural work how 575 have you then implemented those changes hav- what were they 576 what was that like to to go in and /sort of/ /<P4: mmm>/ make the 577 changes after you felt quite stuck	Conflicting Agendas / Expectations of Therapy	
Client wanting something different to what therapist is /can offer	578 P4: um okay then again kind of both on both occasions I think again 579 the person's want from the sessions was just to have someone to talk 580 to so even then implementing the kind of task based approach with 581 the person wasn't helpful because they didn't do it 582 I: mmm and how confident did you feel going into then make 583 changes	Unsuccessful Work	
Un Successful Work Impacting perception	584 P4: err yeah I mean I was ready to give it a go um I suppose after two 585 three sessions it was clear that it wasn't working so then I suppose 586 the next time I'd work with someone with learn- like with a mild 587 learning disability I I I would probably have different expectations 588 from from how it would go potentially	Unsuccessful Work	
Trying to find alternative Services instead of IAPT	589 I: yeah and what might your expectations be 590 P4: err err ( ) that potentially I would probably try and get them 591 community linked into err another service um be awa- I would be 592 aware that it the work wold be more likely to turn into um like a 593 counselling type approach I know that w- I suppose we're not really 594 supposed to do that but on occasions we can we have counsellors 595 here as well so I would look at getting them referred to a counsellor 596 um yeah I suppose I'd be less inclined to work with them	Uncertainty about IAPT / CBT Appropriateness	
More like Counselling rather than CBT	597 I: yep okay and do you think I mean ar- I mean are there sort of clear 598 service agreements within /this/ /<P4: no>/ service about working 599 with people with LD	Conflicting Expectations Agendas of Therapy	
Tensions - between Client + IAPT	600 P4: no	Reluctance to Work With people with LD	
LD not on Agenda in Practice - Lack of Structural / policy guidance?		Unclear Service Agreements / Provision	

16 of 26

## Appendix 13: Description of analytical process

### Appendix 13.1: Identification of initial codes

Following familiarisation of the raw data through re-reading transcripts, hand-written annotations were made to represent initial areas of interest (left hand margin) and phrases/ possible codes were later noted to attempt to capture the essence of what was being said by the participant (right-hand margin). Codes identified from the raw data are shown in the table below. Codes that appeared to relate to each other were grouped next to each other to facilitate the identification of overarching/ higher-order themes. The number of participants for which the code was relevant is also recorded in the frequency column.

#### *List of identified codes*

Code	Frequency
Needing to involve the system (more)	9
Involving the carers can be helpful	6
Challenges of carer involvement	4
Carer involvement needs careful consideration	6
more work 'outside' of the therapy room	6
Adaptations necessary	6
Not 'pure' CBT	3
Using adapted resources	2
Making the work more simplistic	8
More concrete, less abstract	5
More behavioural less cognitive	7
The work is slower and takes longer	6
Creativity: more time drawing, less time talking	6
Doing rather than talking	2
Direction over collaboration	7
Successful work	4
Unrealistic expectations; Fighting for workload adjustments	5
Not enough time to prepare and think	7
Personal costs	7
Positives of the work	1
Blocking it out, but facing repercussion	4
Ethical dilemmas: MDS- 'an ethical nightmare'	4
Ethical dilemmas: Tensions between the needs of the client and IAPT	6
Flexibility but not 'special flexibility' for LD	6
Practical barriers to making adjustments	4
MDS compulsory yet is Inappropriate and unreliable	7
Not enough thought around service delivery	2
LD Missing in Practice: Poor guidance	5
LD Missing in Practice: Little awareness around LD policies	7
LD Missing in Practice: A 'hidden group'	8
Service provision unclear for LD	5
The importance of LD training	7
Concern for Therapists with no LD training or experience	5
IAPT training Leaves you unprepared for LD work	2
A real need for training and support regarding LD work	9
Resource investment isn't worthwhile: A "chicken and egg" scenario	5
Confidence influenced by experience & knowledge	5

Unhelpful supervision and advice	5
Supervision making the work possible	5
External support	3
Poor collaboration with LD services – needs to be developed	6
Referrals influenced by local agencies	2
increased complexity	7
The work is tricky, stressful and overwhelming,	5
The work is different	5
Sensing the learning disability	4
Uncertainty around client's abilities and understanding	5
Uncertainty about client's goals for therapy	3
Feeling de-skilled and out of my depth	6
Feeling more skilled in relational aspects vs content	3
Challenge of involving the system within IAPT's boundaries	6
Unsuccessful work	4
Generalisation difficulties	3
MDS: Demanding (for client and therapist) and inappropriate	6
Memory difficulties	4
Not knowing where to "pitch it" and trial and error	7
Making a leaps is difficult	3
Different perspective about the presenting problem	2
Managing relational boundaries	2
Endings require careful planning	6
Uncertainty around long term utilisation of skills	4
Attendance issues	2
Okay if straightforward	3
Different expectations of therapy, which required careful management	4
Simplistic and short assessment used	1
Uncertainty around client's ability to fit in with recovery expectations	3
Uncertainty around suitability of IAPT for people with LD	6
IAPT (which may not be appropriate) Or nothing (Ethical dilemma)	3
Therapists' frustration around IAPT's broadening remit	2
Clients with LD taking extra resources	1



## Appendix 13.2: Examples of coded data extracts

<p><b>Unrealistic expectations; Fighting for workload adjustments</b></p>	<p>P: I think that there is more the target driven is more stronger so there has to be kind of as fight &lt;I: yeah&gt; to kind of think well how realistic is that so I think sometimes I think that's the difficulty because I think there's it's almost like um a switching off sometimes you feel that in a sense you know you need to be working you know you don't need the time to make the reasonable adjustments because the adjustments had already done been done because when I first started working there were two assistant psychologists that were um employed to help with the bits of work in between like um you know adapting all the tools &lt; I: right I see yeah &gt; but the thing is it's you know every individual's unique and every individual's different so you can't use the same forms for every single person (Pat: 310-321)</p> <p>P: I think in terms of the the managers here I get the impression that they're they're supportive of it as long as it doesn't take away from my normal job if that makes sense so when we have- so for somebody that works five days a week you have to you have like 20 contacts so you have to see 20 people basically so they're all very supportive that's great but but you you don't kind of get an adjustment in terms of your time</p> <p>I: oh you don't</p> <p>P8: well I I fought I didn't for a while and I fought to get one contact adjustment so for my you know I could be seeing five people with learning disabilities and I have one contact adjustment so I've been dropped down- thinking about whole time equivalent it'd be dropped down to 19 instead of 20 so it's not it's not a lot in the grand scheme of things in terms of how much extra time it can take &lt;I: yeah&gt; working with several people with learning disabilities and kind of quite frequently seeking consultation and supervision from and LD team (Alex: 509-526).</p> <p>P: I mean it feels a bit like this black box where you sort of have this magical answer to adapt CBT there isn't magical things you do its just about having the time to do them &lt;I: mmm&gt; and I think that's the other thing I'm bringing in is that if you are seeing people with diagnosis of LD making sure your case load reflects that making sure you've got time built-in to your week to do the prep (Charlie: 1142-1148).</p> <p>P: yeah well I think one of the main things with the IAPT services that our contacts at the moment only seem to be face to face or telephone consultation with clients um there doesn't seem to be um kind of recognition for the all the indirect working that often has to take place particularly around you know groups such as those with learning difficulties I think it is a lot of indirect working and I think one of the main changes would be um ensuring that indirect working has a way to be recorded um and be funded accordingly with how much of that takes place because a lot of our clinicians do a lot of that in terms of linking up with other services getting those services to come to speak to the team and increasing referrals I the connections that that it's part of the job but it goes unrecorded (Jessie: 654-665).</p> <p>P: In IAPT there just really isn't time built into your schedule to do anything other than um admin err you know any any kind of extra reading um you'd be doing in your own time/ I: yeah sure/ yeah (Cameron: 685-688).</p>
<p><b>Challenges of carer involvement</b></p>	<p>P: it was just pretty much the aunty was just talking I: right</p> <p>P: um which I think was probably quite illustrative of the problem which was helpful in terms of my understanding but you could just see the client's frustration it was just building because she was so keen to seek help but it's just that the aunty was saying you know oh she does this she feels this she thinks this and yeah it wasn't</p> <p>I: yeah so how did you manage that</p> <p>P: it was quite tricky um and don't get me wrong we do get that here err kind of people's husbands or whatever wives um I think maybe just being very tactful um and explaining that normally this type of therapy it is one to one and whilst it's good to have her there for support um it is also good just to have space and just us and just kind of very [laughs] very nicely pushed her away (Emma: 504-517).</p>

	<p>P: I often feel that I am probably being a bit more abrupt than maybe I am because I do say like very honestly that you know I always try to confront the referred person I'd say look what do you think about the idea and I do and I also say to them what do you think about that what I think it will add in the moment or if I feel they haven't if I feel really they're really lost in the conversation sometimes just always bringing it back and being prepared to be quite honest with people I'm really not fussed I say look this is a shared space for everyone to talk so if I feel I'm not hearing someone I might ask them what their thoughts are so I try and be transparent um but yes it's a tough one it's hard to manage sometimes (Charlie: 775-786).</p> <p>P: the key difference was that his mum kept speaking on his behalf and the few things that that he got a chance to say before she interrupted to explain what he was saying I actually got the sense that he could actually explain a lot of things quite well um but she was obviously very keen to let me know how bad he'd been and so she was talking on his behalf a lot (Rory: 88-93).</p> <p>P: I think she got pretty pissed off [laughs] with me about that cos she um she wanted to know what was going on and I I even to this day I don't know whether that would have been helpful or not um there were times were I felt like she was just being a bit more involved than she needed to be (Rory: 905-909).</p> <p>P: we kind of set it up that um that I mainly interacted with him um I I was very aware that I didn't want to set it up that you know that I was talking to her about him um you know I kind of very much wanted to set it up that you know I was there to see him and and that I wanted to hear from him about his point of view (Cameron: 255-260)</p>
<b>Not enough time to prepare and think</b>	<p>P: there's very little reflecting which you and it's a very new experience for me because I'm used to secondary working in the /secondary care/ /&lt;l: yeah sure&gt;/ and you do have more time to process um so that can be very very stressful I /&lt;l: mmm&gt;/ /um/ and difficult um but &lt;l: not having the time&gt; not having the time but I have had time because in a sense um you know it depends on how long it takes for them to give me new referrals and then sometimes a person doesn't turn up so it's almost like being reliant relying on sort of somebody not turning up or the fact that may have seen somebody but they might not be appropriate for the service so you've got a bit of a gap to reflect (Pat: 286-296).</p> <p>P: In an IAPT service we're very pushed we have a large amount of contacts that we're supposed to make each week we see people back to back and I know that I don't always have the time to attend to the nuances and the uniqueness as much as I would like to if I had more capacity and time to reflect and think &lt;l: yeah&gt; so therefore often you are just kind of winging it or doing your best or drawing on um the skills that you've kind of internalised over the years and delivering therapy that you've delivered before and have you know it's or that's very similar so you kind of have models in your mind and you might be able to tweak them for the individual but your still drawing on the models and when you need to make a big leap from what you normally do that might be more difficult (Kelly: 343-352)</p> <p>I: what was that like feeling like you needed to you know that being really important to be able to liaise with other agencies but being within the IAPT remit was that like?  P: yeah it was it was really tough because I I struggle at the best of times to get all my admin done you know to find the time to just do routine admin so with cases such as these I find it such a struggle to find that time and it it sounds awful but you kind of you hope you hope and rely on people cancelling or not turning up to sessions to do some of that extra work (Jessie: 274-283).</p> <p>P: it's kind of lots of calls and contacting the GP and there's lots that then takes up huge portion of your time &lt;l: yeah&gt; on top of that you're trying to get your to meet your targets from your normal role um and um yeah and just the there's another person ... there's kind of multiple risk issues with with one person and I think because they would be considered to as a vulnerable adults so that has to go down a particular route so again it's again something that is difficult (Alex: 443-455).</p>

### **Appendix 13.3: Identification of potential higher-order themes**

Following the creation of initial codes and identification of possible relationships through clustering codes together, a number of potential themes were generated in order to further group and make sense of the initial codes. The table below shows the fifteen potential higher-order themes created. Initial code names which were collapsed to create the higher-order theme were retained to describe what information was conveyed within the theme. This was a recursive process, and raw data were consistently checked against each theme to ensure the interpretations were grounded in observable data.

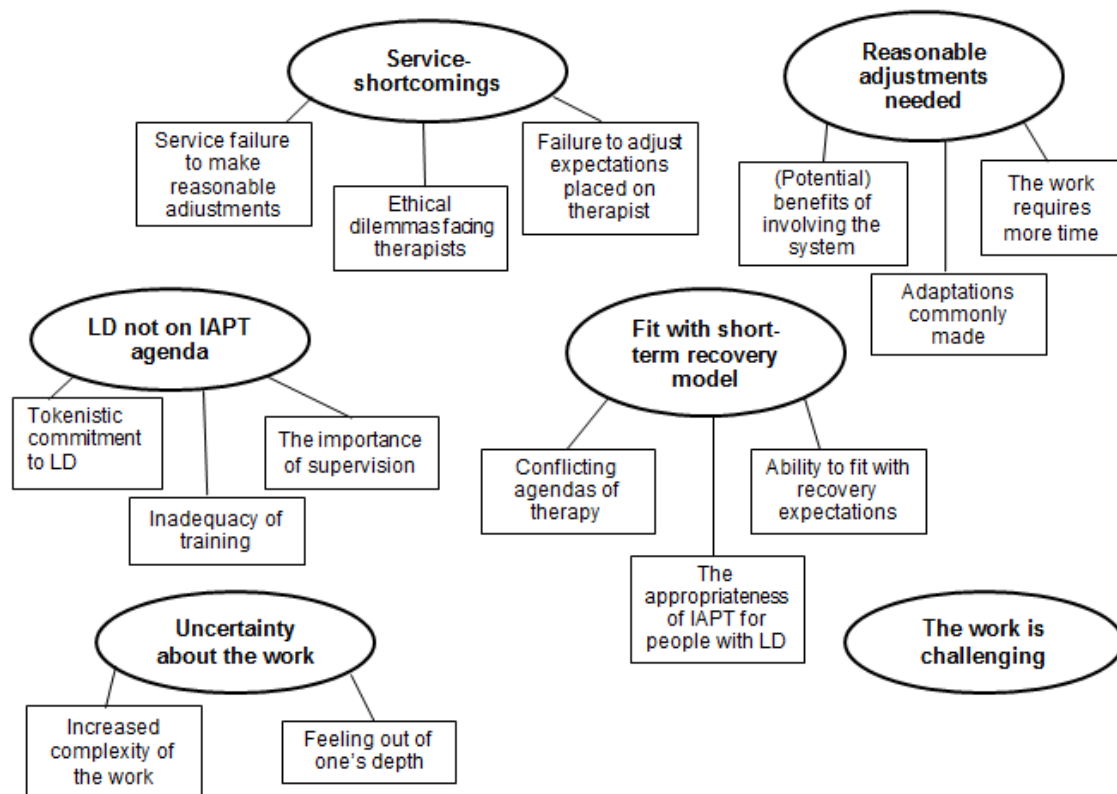
#### *List of identified higher-order themes and grouped initial codes*

<b>Higher order theme</b>	<b>Grouped initial codes</b>
<b>(Potential) benefits of involving the system</b>	<ul style="list-style-type: none"> <li>– Needing to involve the system (more)</li> <li>– Involving the carers can be helpful</li> <li>– Challenges of carer involvement</li> <li>– Carer involvement needs careful consideration</li> </ul>
<b>The work requires more time</b>	<ul style="list-style-type: none"> <li>- More work outside of the therapy room</li> </ul>
<b>Adaptations: commonly made</b>	<ul style="list-style-type: none"> <li>– Adaptations necessary (context)</li> <li>– Not ‘pure’ CBT</li> <li>– Using adapted resources</li> <li>– Making the work more simplistic</li> <li>– More concrete, less abstract</li> <li>– More behavioural less cognitive</li> <li>– The work is slower and takes longer</li> <li>– Creativity: More time drawing, less time talking</li> <li>– Doing rather than talking</li> <li>– Direction over collaboration</li> <li>– Successful work</li> </ul>
<b>Service failure to adjust expectations placed on therapist</b>	<ul style="list-style-type: none"> <li>– Unrealistic expectations; fighting for workload adjustments</li> <li>– Not enough time to prepare and think</li> <li>– Personal costs</li> <li>– Positives of the work</li> </ul>
<b>Ethical dilemmas</b>	<ul style="list-style-type: none"> <li>– Blocking it out, but facing repercussion</li> <li>– Ethical dilemmas: MDS- ‘an ethical nightmare’</li> <li>– Ethical dilemmas: Tensions between the needs of the client &amp; IAPT</li> </ul>
<b>Service failure to make reasonable adjustments</b>	<ul style="list-style-type: none"> <li>– Flexibility but not ‘special flexibility’ for LD</li> <li>– Practical barriers to making adjustments</li> <li>– MDS compulsory yet is inappropriate and unreliable</li> </ul>
<b>Tokenistic commitment to LD in IAPT</b>	<ul style="list-style-type: none"> <li>– Not enough thought around service delivery</li> <li>– LD Missing in Practice: Poor guidance</li> <li>– LD: Missing in Practice: Little awareness of policies</li> <li>– LD Missing in Practice: A ‘hidden group’</li> <li>– Service provision unclear for LD</li> </ul>
<b>Inadequacy of training</b>	<ul style="list-style-type: none"> <li>– The importance of LD training</li> <li>– Concern for Therapists with no LD training or experience</li> <li>– IAPT training leaves you unprepared for LD work</li> <li>– A real need for more training and support regarding LD work</li> <li>– Resource investment isn’t worthwhile: A “chicken &amp; egg” scenario</li> <li>– Confidence influenced by experience &amp; knowledge</li> </ul>

<b>Supervision issues</b>	<ul style="list-style-type: none"> <li>– Unhelpful supervision and advice</li> </ul>
<b>The Value of Supervision</b>	<ul style="list-style-type: none"> <li>– Supervision making the work possible</li> </ul>
<b>Value of external support</b>	<ul style="list-style-type: none"> <li>– External support</li> <li>– Poor collaboration with LD services – needs to be developed</li> </ul>
<b>Increased complexity of the work</b>	<ul style="list-style-type: none"> <li>– Referrals influenced by local agencies</li> <li>– Increased complexity</li> <li>– The work is tricky, stressful and overwhelming</li> <li>– The work is different</li> <li>– Sensing the learning disability</li> <li>– Uncertainty around client's abilities and understanding</li> <li>– Uncertainty about client's goals for therapy</li> </ul>
<b>Lacking confidence</b>	<ul style="list-style-type: none"> <li>– Feeling deskilled and “out of my depth”</li> <li>– Feeling more skilled in relational aspects vs content</li> </ul>
<b>Common difficulties in delivering CBT</b>	<ul style="list-style-type: none"> <li>– Challenges of involving the system within IAPT's boundaries</li> <li>– Unsuccessful work</li> <li>– Generalisation difficulties</li> <li>– MDS: Demanding (for client and therapist) and inappropriate</li> <li>– Memory difficulties</li> <li>– Not knowing where to “pitch it” and trial and error</li> <li>– Making a leap is difficult</li> <li>– Different perspectives about the problem</li> <li>– Managing relational boundaries</li> <li>– Endings require careful planning</li> <li>– Uncertainty around long term utilization of skills</li> <li>– Attendance issues</li> <li>– Okay if straightforward</li> </ul>
<b>Fit with short-term recovery model</b>	<ul style="list-style-type: none"> <li>– Different expectations of therapy which require careful management</li> <li>– Simplistic and short assessment used</li> <li>– Uncertainty around client's ability to fit in with recovery expectations</li> <li>– Uncertainty around suitability of IAPT for people with LD</li> <li>– IAPT (which may not be appropriate) or nothing (ethical dilemma)</li> <li>– Therapists' frustration around IAPT's broadening remit</li> <li>– Clients with LD taking extra resources</li> </ul>

## **Appendix 13.4: Thematic Map 1**

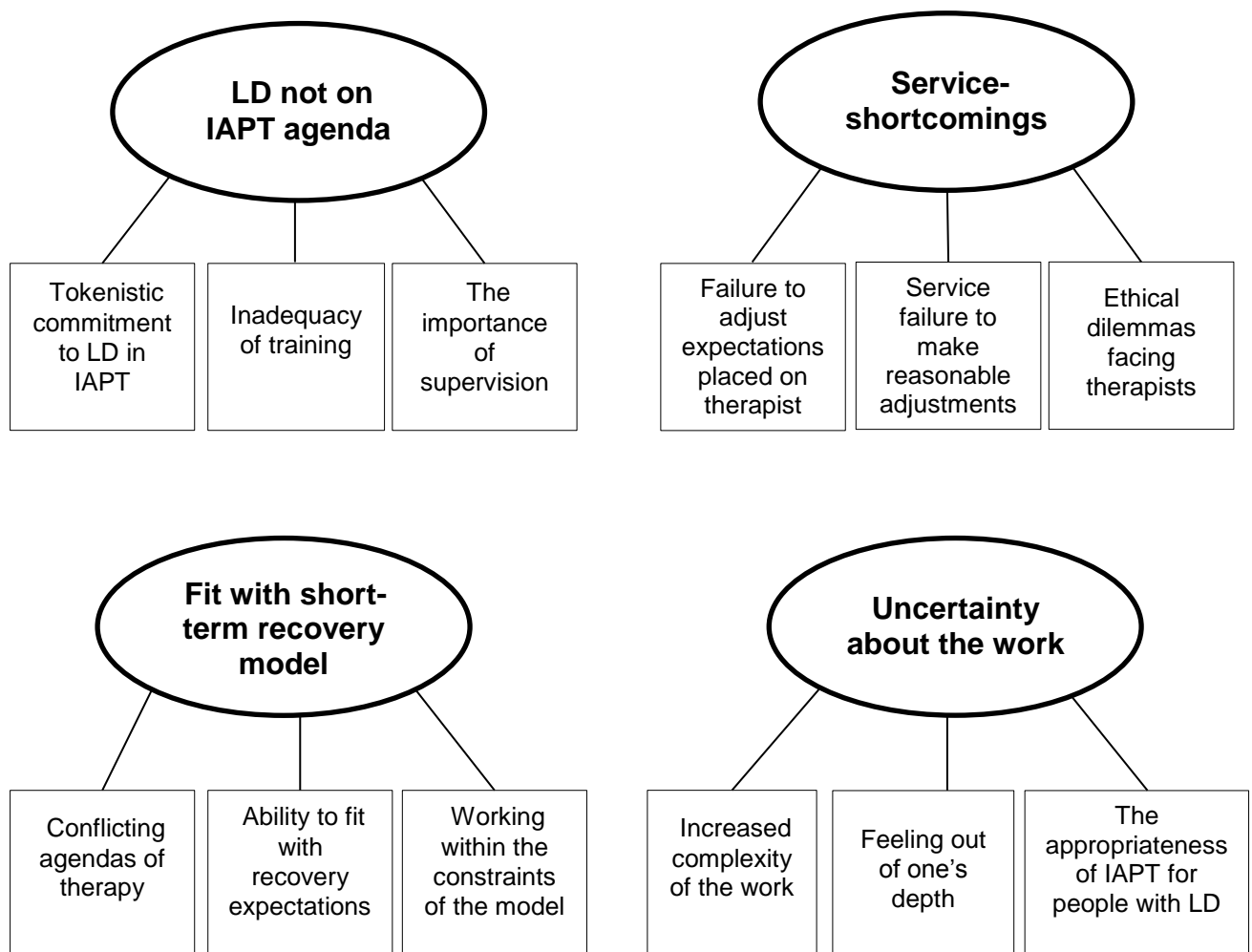
Following the identification of fifteen potential higher-order themes, these were further collapsed into six themes to represent the raw data. Thematic Map 1 depicts the themes and relevant subthemes generated.



**Thematic Map 1**

## **Appendix 13.5: Thematic Map 2 (Final)**

Internal and external homogeneity was assessed for the six themes shown in Thematic Map 1. It was decided that data within 'the work is challenging' could be held within other higher-order themes such as 'service short-comings' and 'uncertainty about the work', which would reflect the stories told by participant more closely. On closer examination of the higher-order theme 'reasonable adjustments needed', it was decided that the data within this theme could be captured within a separate sub-theme ('working within the constraints of the model') under the higher-order theme of 'fit with short-term recovery model' and in the sub-theme 'Ability to fit with recovery expectations'. The sub-theme 'the appropriateness of IAPT for people with LD' was considered to be more relevant to the information depicted within the theme 'uncertainty about the work' and was therefore moved to this theme. The final thematic map depicting themes and sub-themes which were felt to best represent the data can be seen in Thematic Map 2.



**Thematic Map 2 (Final)**